S. HRG. 99-764

PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS

HEARING

BEFORE THE

SELECT COMMITTEE ON INDIAN AFFAIRS UNITED STATES SENATE

NINETY-NINTH CONGRESS

SECOND SESSION

ON

S. 1988

TO ESTABLISH A PROGRAM FOR THE PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS

APRIL 15, 1986

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PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS

TUESDAY, APRIL 15, 1986

U.S. SENATE,
SELECT COMMITTEE ON INDIAN AFFAIRS,
Washington, DC.

The committee met, pursuant to notice, at 9:30 a.m., in room 385 Russell Senate Office Building, Hon. Mark Andrews (chairman of the committee) presiding.

Present: Senators Andrews, Melcher, Inouye, and Burdick.

Staff present: Peter S. Taylor, staff director; Max Richtman, minority staff director; Patricia Zell, staff attorney; Luis De Ortube, professional staff member; Mary Jo Urem, professional staff member; Sheila Rogan, professional staff member; Ipo Lung, professional staff member; June Tracy, professional staff member; and Christine Drayton, secretary.

The CHAIRMAN. Good morning. The committee will come to order.

I am pleased to join my colleague from Montana in sponsoring this important legislation that addresses one of the most significant health problems among native Americans today, the problem of diabetes and its associated complications.

This is a problem that has reached alarming proportions in the native population around the country, and in my home State of North Dakota. On the Fort Berthold Reservation in North Dakota the rate of deaths from diabetes is 123.8 per 100,000 population, a rate which is staggering when compared to the 9.6 per 100,000 population of deaths resulting from diabetes in the United States for all races. On the Fort Totten Reservation, the rate of deaths from diabetes is 87.4 per 100,000; and on the Turtle Mountain Reservation, the rate is 42.2 per 100,000.

These are just selected examples of the magnitude of the diabetes problem in the State of North Dakota. I am submitting for the record a chart which indicates the extent of the diabetes death rate in the Indian population nationally, as well as for other tribes in the Aberdeen area of the Indian Health Service System.

[Material referred to appears in the appendix.]

The CHAIRMAN. Given the serious nature and extent of diabetes in the native American population, it is particularly surprising that the administration is officially in opposition to this bill on the grounds that a legislative initiative aimed at the prevention and control of diabetes would, and I quote, "narrow the focus of Federal

efforts to improve the health status of Indians by drawing limited funds from other priority projects."

It seems to me that the statistics alone would indicate that whatever the IHS is currently doing to address the problem of diabetes, that effort needs to be supplemented and expanded. S. 1988 provides for the expansion of existing HIS model diabetes clinics, and authorizes research on diabetes and its associated complications, as well as outreach activities to educate native Americans in the prevention and control of diabetes. I believe this legislation is needed, and I strongly support it.

[The text of S. 1988 follows:]

II

99TH CONGRESS
1ST SESSION

S. 1988

To establish a program for the prevention and control of diabetes among Native Americans.

IN THE SENATE OF THE UNITED STATES

DECEMBER 19 (legislative day, DECEMBER 16), 1985

Mr. MELCHER (for himself, Mr. INOUYE, Mr. DECONCINI, Mr. BURDICK, Mr. ANDREWS, Mr. ABDNOR, and Mr. BINGAMAN) introduced the following bill; which was read twice and referred to the Select Committee on Indian Affairs

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A BILL

To establish a program for the prevention and control of diabetes among Native Americans.

Be it enacted by the Senate and House of Representatives of the United States of America in Congress assembled, That this Act may be cited as the "Native American Diabetes Prevention and Control Act of 1985".

FINDINGS AND PURPOSE

SEC. 2. (a) The Congress finds that—

(1) the incidence of diabetes among Native Americans (which for purposes of this Act includes Indians, Native Alaskans, and Native Hawaiians) is significant-

ly higher than in other population groups within the United States;

(2) in several Indian tribes over 40 percent of the adults have diabetes compared with approximately 3 percent of the overall United States adult population;

(3) diabetes has become the second leading reason for outpatient visits by Native Americans to Indian Health Service facilities nationwide;

(4) serious complications of diabetes, such as kidney failure, hypertension, amputation, and blindness, are increasing in frequency among Native Americans;

(5) health care costs for treatment of diabetes and related complications among Native Americans will increase significantly in the long term unless the Department of Health and Human Services (hereinafter referred to as the "Department")—

(A) determines the cause of diabetes among Native Americans,

(B) develops early diagnosis, treatment, and prevention programs to reduce the incidence of diabetes among Native Americans, and

(C) trains, or provides for the training of, Federal and Native American health care providers in the diagnosis, treatment, and control of diabetes and related complications;

(6) a Model Diabetes Control Program exists within the Indian Health Service, consisting of seven project sites which serve only 10 percent of the Indian Health Service patients; and

(7) outreach services and the conveyance of effective treatment strategies from the model project sites need to be implemented.

(b) The purposes of this Act are—

(1) to broaden the research program of the Department relating to diabetes and related complications among Native Americans;

(2) to strengthen the efforts of the Indian Health Service for the treatment of diabetes through the implementation of a program for the prevention and control of diabetes and related complications on each Indian Reservation, for each Alaskan Native Village, and in Hawaii; and

(3) to achieve a reduction in the incidence of diabetes among Native American populations to a rate comparable to that of the general United States population.

STUDY ON DIABETES AMONG NATIVE AMERICANS

SEC. 3. (a) The Secretary of Health and Human Services (hereinafter referred to as the "Secretary") shall determine—

(1) the incidence of diabetes among Native Americans;

(2) activities the Indian Health Service should take—

(A) to reduce the incidence of diabetes among Native Americans,

(B) to provide Native Americans with guidance in the prevention, treatment, and control of diabetes,

(C) to provide early diagnosis of diabetes among Native Americans, and

(D) to ensure that proper continuing health care is provided to Native Americans who are diagnosed as diabetic; and

(3) the fiscal impact to the Federal Government of treating the long-term complications of diabetes based upon the existing prevalence and incidence of diabetes among Native Americans.

(b) The Secretary shall prepare an inventory of all health care programs and resources (public and private) within the United States that are available for the treatment, prevention, or control of diabetes among Native Americans.

(c) Within 18 months after the date of enactment of this Act, the Secretary shall prepare and transmit to the President and the Congress a report describing the determinations

made under subsection (a), containing the inventory prepared under subsection (b), and describing the research activities conducted under section 6.

DIABETES CARE PROGRAM

SEC. 4. (a) Within 18 months after the date of enactment of this Act, the Secretary shall implement a program designed—

(1) to strengthen and expand the diabetes control program of the Indian Health Service;

(2) to enable all service units of the Indian Health Service to treat effectively—

(A) newly diagnosed diabetics in order to reduce future complications from diabetes,

(B) individuals who have a high risk of becoming diabetic in order to reduce the incidence of diabetes, and

(C) short-term and long-term complications of diabetes;

(3) to conduct, for Federal, tribal, and other Native American health care providers (including community health representatives), training programs concerning current methods of prevention, diagnosis, and treatment of diabetes and related complications among Native Americans;

(4) to determine the appropriate delivery to Native Americans of health care services relating to diabetes;

(5) to develop and present health education information to Native American communities and schools concerning the prevention, treatment, and control of diabetes; and

(6) to ensure that proper continuing health care is provided to Native Americans who are diagnosed as diabetic.

(b) The Secretary shall—

(1) promote coordination and cooperation between all health care providers in the delivery of diabetes related services; and

(2) encourage and fund joint projects between Federal and tribal health care facilities and Native American communities for the prevention and treatment of diabetes.

(c)(1) The Secretary shall continue to maintain each of the following model diabetes clinics which are in existence on the date of enactment of this Act:

(A) Claremore Indian Hospital in Oklahoma;

(B) Fort Totten Health Center in North Dakota;

(C) Sacaton Indian Hospital in Arizona;

(D) Winnebago Indian Hospital in Nebraska;

(E) Albuquerque Indian Hospital in New Mexico;

(F) Terry, Princeton, and Old Town Health Centers in Maine; and

(G) Bellingham Health Center in Washington.

(2) Within 2 years after the date of enactment of this Act, the Secretary shall establish and maintain a model diabetes clinic in each of the following locations:

(A) the Navajo Reservation;

(B) the Papago Reservation;

(C) Montana;

(D) Minnesota; and

(E) Hawaii.

(3) The Secretary shall develop and implement an outreach program to ensure that the achievements and benefits derived from the activities of the model diabetes clinics maintained under this section are used by all service units of the Indian Health Service in the diagnosis, prevention, and treatment of diabetes among Native Americans.

(d) The Secretary shall maintain appropriate personnel within the Indian Health Service to develop and implement the provisions of this Act and to manage and coordinate the diabetes care program of the Indian Health Service.

(e) The Secretary shall submit to the Congress an annual report outlining the activities, achievements, needs,

and future goals of the diabetes care program of the Indian Health Service.

DATA COLLECTION AND ANALYSIS

SEC. 5. The Secretary shall develop and maintain a comprehensive standardized system within the Indian Health Service to collect, analyze, and report data regarding diabetes and related complications among Native Americans. Such system shall be designed to facilitate dissemination of the best available information on diabetes to Native American communities and health care professionals. Such system shall be operational within 2 years after the date of enactment of this Act.

RESEARCH

SEC. 6. The Secretary shall require each agency and unit of the Department which conducts research relating to diabetes—

(1) to give special attention to research concerning the causes, diagnosis, treatment, and prevention of diabetes and related complications among Native Americans; and

(2) to coordinate such research with all other agencies and units of the Department which conduct research relating to diabetes and related complications.

REGULATIONS

SEC. 7. The Secretary may prescribe such regulations as may be necessary to carry out the provisions of this Act.

AUTHORIZATION OF APPROPRIATIONS

SEC. 8. There are authorized to be appropriated such sums as may be necessary to carry out the provisions of this Act.

○

The CHAIRMAN. I want to reconginze the fact that my distinguished colleague, the Senator from Hawaii, is here, and because I know he has other commitments, I would be glad to have his statement at this point in time.

Senator Inouye, it's always good to have you here. I know that what you have to say will be of great import to this committee and to our native American friends around the country. We will be glad to hear from you.

STATEMENT OF HON. DANIEL K. INOUYE, U.S. SENATOR FROM HAWAII, AND MEMBER, SENATE SELECT COMMITTEE ON INDIAN AFFAIRS

Senator INOUYE. Mr. Chairman, thank you very much. You are most courteous at all times.

Mr. Chairman, obviously I appear here this morning to speak in support of S. 1988. Mr. Chairman, the serious health status of native Hawaiians has been a matter of major and ever-increasing concern. At the turn of this century the native Hawaiian population declined so precipitously that it was believed then that this group might not survive at all. Due, in part, to the actions of the Federal Government as early as the 1920's on behalf of this native population, but due moreover to their own tenacity and will to survive, their numbers have steadily increased. Currently, native Hawaiians represent approximately one-fifth of all persons in the State of Hawaii and one-sixth of all native Americans.

Unfortunately, their health status remains far below that of the native population as a whole. Their life expectancy is about 10 years below that of others in the State of Hawaii, and they suffer disproportionately from major chronic illnesses such as heart disease, cancer, and diabetes.

A comprehensive study of the health needs of native Hawaiians was recently completed, and this study found that diabetes ranks as the third leading cause of death for native Hawaiians. Data from the State Department of Health shows that since 1910 native Hawaiians have had the highest mortality from diabetes of all groups in the State, while four times greater.

Both prevalence and mortality rates are misleading, however, since diabetes, known as the "silent killer," often goes undetected and is manifest in other diseases such as arteriosclerosis and kidney failure. Native Hawaiians, for example, represent approximately 40 percent of all end-stage renal disease patients in the State.

The U.S. Department of Health and Human Services recently issued the report of the Secretary's Task Force on Black and Minority Health. This report confirms the very high prevalence of diabetes among native Americans, suggests that about half the cases of diabetes among Americans are likely to be unreported, recommends additional research on the prevalence of diabetes and its complications among minorities, and emphasizes the importance of health education and early recognition of this disease.

And, Mr. Chairman, as we all know, these are all aspects of the bill you have just introduced, S. 1988. Its provisions would directly

address the severe need among all native Americans, including native Hawaiians in the State of Hawaii.

So, Mr. Chairman, I congratulate you on your wisdom in introducing this measure, and I am pleased to add my support for S. 1988.

The CHAIRMAN. Thank you, Senator, for your strong support of this legislation, and as a valued member of this select committee I hope that our native Americans realize how important your support is to getting this much needed legislation through. We appreciate your testimony here today.

Senator INOUYE. Thank you very much, sir.

The CHAIRMAN. Our next witness is the Senator from New Mexico, Mr. Bingaman. We're glad to have you here.

STATEMENT OF HON. JEFF BINGAMAN, U.S. SENATOR FROM NEW MEXICO

Senator BINGAMAN. It's nice to be here. Thank you, Mr. Chairman.

Let me commend the Senate Select Committee on Indian Affairs for holding this hearing on an important issue, the disease that strikes 10.6 million Americans and in particular afflicts American Indians. Diabetes can, in general, be prevented and controlled, and I wholeheartedly support S. 1988 because it attempts specifically to prevent and control diabetes in the Indian community.

I want to commend you, Mr. Chairman, and Senator Melcher for leadership in introducing this legislation, and I am proud to cosponsor it.

The recent report which Senator Inouye referred to, states that diabetes was the seventh leading cause of death in the United States in 1980 and one of the six major contributors to the disparity in health status between minorities and nonminorities. As you know, Mr. Chairman, I have introduced S. 400, the Indian Health Promotion and Disease Prevention Act, and in a field hearing held last year by this committee on the bill, Bruce Leonard of the Indian Health Service, who testified and who will testify again today, reported that 1 Indian in every 4 adults will develop diabetes as compared to 1 in 20 in the population at large. This startling statistic points to the fact that something must be done to attack this problem in the Indian community.

S. 1988 would establish a program for the prevention and control of diabetes. First, the bill requires a study and then, within 18 months after enactment of the measure, a diabetes program would be established to strengthen and expand the existing programs and services of the Indian Health Service.

The current IHS model diabetes control program would continue. At present, seven project sites serve approximately 10 percent of the Indian Health Service patient population. Five new sites would be added, and finally, diabetes data collection and analysis plus research would be developed and maintained.

The legislation to control diabetes among Indians is critical and necessary, and I support it wholeheartedly. But I want to urge that while we seek to prevent and control diabetes, we must not miss seeing the even broader health needs of the Indian community.

While we are dealing with what amounts to a diabetes epidemic, we must not overlook the importance of promoting health and preventing disease in the broader sense among Indian tribes. The significance of diabetes as a health problem becomes more important because of its association as a risk factor for other major diseases. Because of the close association of diabetes with obesity, and the known importance of diet and exercise to control one's weight, this knowledge should be broadened in the Indian community to encompass the prevention of heart disease, of stroke, of cancer, and of other related diseases. Health promotion and disease prevention provide a frame work for us to accomplish this.

Mr. Chairman, the best example I know of a communitywide health promotion program aimed at native Americans is the Zuni diabetes project, established in 1983 under the leadership of Bruce Leonard at Zuni, NM. Interestingly, this community is not one of the five IHS model diabetes project sites. I am pleased that Bruce will appear today with other IHS officials. I hope the committee will take special note of the successes that that program has had. The combination of diet and exercise at Zuni has enabled 20 diabetics to be taken off of insulin. They now report normal blood sugars. A total of 200 Zunis participate in daily aerobics classes at the pueblo, and the exercise classes are supplemented by educational classes which provide information about physiology, nutrition, exercise, and other diabetes-related topics.

Although this Zuni project is oriented toward diabetes, it presents a clear example of community involvement and ownership and how positive lifestyle behaviors are being reinforced to prevent disease. In addition to expanding our understanding of diabetes, we perhaps ought to replicate such models in other Indian communities.

I wish to impress upon this committee may concern that we pass a comprehensive Indian health care bill that includes a health promotion element before this Congress adjourns. As we all know too well, last year, the version which was approved by Congress was vetoed by the President. Time is of the essence, since it's already April and we expect an early adjournment.

In closing, I would like to say that the committee today will also be hearing testimony by Dr. Neal Friedman, president of the New Mexico Diabetes Association. Dr. Friedman has also worked in the Indian community. For 2 years he served in the Indian Health Service clinic at the Zuni Pueblo. He too deserves the attention and support of this committee. I am sure that he will offer constructive and useful testimony to you.

Thank you for the opportunity to testify today, Mr. Chairman.

The CHAIRMAN. Thank you, Senator, for an excellent statement and for your support of this legislation. We value your testimony here today, and it will be most helpful to us.

Senator BINGAMAN. Thank you.

The CHAIRMAN. Next, because they're here and because Senator Inouye is here and is going to another meeting, I would like to call up Mr. Kamaki Kanahele, administrator of the Office of Hawaiian Affairs, and Dr. David Johnson, the Native Hawaiian Health Research Consortium, University of Hawaii.

Senator INOUYE. Mr. Chairman, may I join you in welcoming our witnesses?

The CHAIRMAN. You certainly may, Senator.

Senator INOUYE. Mr. Chairman, I am certain the committee is not aware, but we have today a very distinguished citizen of the State of Hawaii. He is the descendant of the Great Aliis of the Great Alii Nuis of Hawaii, and I think we are honored with his presence here. He was recently elected to serve as administrator of OHA, the Hawaiian Office of Hawaiian Affairs. And I think the State of Hawaii can anticipate great things from the leadership of Mr. Kanahele.

I would like to join you, Mr. Chairman, in welcoming Mr. Kanahele and Dr. Johnson.

The CHAIRMAN. It's good to have you both here. Let me assure you that your entire written testimony will be put in the record as though it was uttered, every word. You may summarize it in any way you think would be helpful.

STATEMENT OF KAMAKI KANAHELE, ADMINISTRATOR, OFFICE OF HAWAIIAN AFFAIRS

Mr. KANAHELE. Good morning, Mr. Chairman, and [inaudible] Senator Inouye and members of the committee. My name is Kamaki Kanahele III, and I am the administrator of the Office of Hawaiian Affairs. I would like to thank Senator Mark Andrews, chairman of this committee, for scheduling this important hearing. The Office of Hawaiian Affairs strongly supports adoption of S. 1988.

Before continuing, however, I would like to share with you a little background on the Office of Hawaiian Affairs, as it is only 6 years old and as a means of providing the members of the committee with some understanding of the role and interests of OHA, as the acronym reads, in this matter.

The Office of Hawaiian Affairs is governed by an elected nine-member board of trustees. The trustees must be of native Hawaiian descent and are elected by eligible voters who also must be of native Hawaiian ancestry. As a result, the OHA trustees are directly accountable to their beneficiaries and the native Hawaiian people.

OHA was created in 1978 by an amendment of the Hawaii State Constitution. The basis for its establishment, however, dates back to our State Admissions Act of 1959. The act created a public land trust, the proceeds of which were to be used for five purposes. One of the purposes was for the betterment of conditions of native Hawaiians.

In 1979 the State legislature passed act 196, which established the basic structure of OHA. This act, which was subsequently codified as chapter 10, Hawaii Revised Statutes, set out the basic purposes, powers, duties, and responsibilities of OHA. For your convenience, a copy of chapter 10 is attached as appendix A.

[Chapter 10 appears in prepared statement.]

Mr. KANAHELE. chapter 10 established OHA as the principal public agency in this State responsible for the performance, development, and coordination of programs and activities relating to

native Hawaiians. Chapter 10 also mandates OHA to serve as the receptacle for reparations and to act as a clearinghouse for Federal or State assistance in involving Hawaiian programs and projects.

OHA is also responsible for advising, informing, and coordinating Federal, State, and county activities relating to native Hawaiian programs. It is with this role in mind that OHA submits this very important testimony today, S. 1988.

The provisions of S. 1988 that affect native Hawaiians are those that charge the Secretary of Health and Human Services to conduct a study to determine the incidence of diabetes among native Americans, including native Hawaiians; the activities that will reduce the incidence of diabetes, guidelines in the prevention, treatment, and control of diabetes, activities to provide early diagnosis and to ensure proper continuing health care for diabetic native Americans.

The mandated study also includes an examination of the physical impact to the Federal Government on long-term complications of diabetes and an inventory of all health care programs and resources for the prevention, treatment, and control of diabetes among native Americans.

S. 1988 further directs the Secretary of Health and Human Services to implement a diabetes care program which will provide training for health care providers, determination of appropriate delivery of diabetes health care services to native Americans, the development and presentation of relevant health care information, proper health care to diabetic native Americans, and model diabetic clinics, including one in Hawaii. S. 1988 also requires the Secretary to conduct and coordinate research, data collecting, and analysis within the department regarding diabetes among native Americans.

S. 1988 and its provisions enumerated above are specifically important to native Americans who suffer from diabetes more frequently than any other ethnic group in the State. According to a recent study funded by the U.S. Department of Health and Human Services, E Ola Mau, the native Hawaiian health needs study, and in which OHA participated, native Hawaiians have been found to have the highest prevalence of diabetes of any other ethnic group in the State. The chapter on diabetes from E Ola Mau is attached as appendix B.

[Appendix B appears in prepared statement.]

Mr. KANAHELE. In addition, many factors associated with diabetes are characteristic in the Hawaiian population. For example, E Ola Mau found that increased frequency of diabetes appears to be associated with native Hawaiian ethnicity, residing in a rural area, and, if a woman, coming from a lower income family, low education attainment, diet, and body weight are also mentioned as important factors in diabetes.

Native Hawaiians are found in higher concentration in rural areas, have one of the lowest family incomes and education attainment in the State, maintain unhealthy diets, and have more problems with obesity than any other ethnic group in the State.

The E Ola Mau also found that wherever native Hawaiians participate in diabetes screening, they test positive more often than most ethnic groups. Diabetes is the principal cause of death among

native Hawaiians to the extent that native Hawaiians diabetes mortality rates were twice the rates of the general population. In addition, diabetes was found to limit the amount and kinds of activity for native Hawaiians more than for non-native Hawaiians.

Besides identifying the problems of diabetes in the native Hawaiian community, E Ola Mau suggests actions that can be taken to help alleviate the problem. These suggestions are closely aligned with the provisions of S. 1988.

As requested, Mr. Chairman, I would like to switch down to the last parts of this summary, because it will be submitted for the record, and it is most appreciated.

In summary, I would like to reiterate OHA's support for the adoption of S. 1988. Diabetes is a major health problem in the native Hawaiian community, and this proposed Federal legislation would make it possible for native Hawaiians to address this problem in a systematic and meaningful fashion.

I would also like to emphasize that in implementing S. 1988, that special attention be given to the manner in which these programs are delivered. Cultural barriers have to be overcome in the manner of delivery of health care services to native Hawaiians.

The Office of Hawaiian Affairs would like to express its appreciation to this committee for allowing us the opportunity to provide testimony on this most important subject.

[Prepared statement of Mr. Kanahele appears in the appendix.]

The CHAIRMAN. Thank you very much for an excellent statement.

Senators, should we have the second witness before we question?

Senator BINGAMAN. Yes, Mr. Chairman.

Senator INOUYE. Yes, Mr. Chairman.

The CHAIRMAN. Well, we're glad to hear now from you, Dr. Johnson. Let me assure you that you can summarize your statement in any way you wish, and that will leave a little bit more time for questions. But we can assure you that it will appear in the record as though you had given it, every word.

Doctor?

STATEMENT OF DR. DAVID JOHNSON, NATIVE HAWAIIAN HEALTH RESEARCH CONSORTIUM, UNIVERSITY OF HAWAII AT MANOA, HONOLULU

Dr. JOHNSON. Thank you, Senator Andrews and members of the Senate Select Committee on Indian Affairs. My name is David Johnson. And I am testifying in support of S. 1988 on behalf of the Hawaiian Health Research Consortium. This Consortium is coordinated by Alu Like and includes members from the native Hawaiian institutions and agencies and from public and private research, educational, and health institutions and agencies.

As was referred to by Mr. Kanahele's testimony, this Hawaiian Health Needs Study identified Hawaiians as having the highest prevalence of diabetes among ethnic groups in Hawaii.

I would like to skip through my testimony and indicate that native Hawaiians are diagnosed with diabetes at later stages of the disease than the general population because of the unavailability of, and/or reluctance to obtain, regular medical checkups. Medical

help is not sought unless severe symptoms exist, which means that for many native Hawaiians the effects of diabetes are irreversible and catastrophic. This translates into higher proportions of native Hawaiians suffering from retinopathy, end-stage renal disease, arteriosclerosis, and other diseases, more so than other members of the State. It also means that the costs both in terms of suffering and expenditures of economic and medical resources are higher.

I also serve as the executive director of the End-Stage Renal Disease Program in Hawaii, and about 200 to 250 Hawaiians suffer from end-stage renal disease in our State, which represents about 40 percent of the total participants in that program. If we had an adequate prevention program, we could save in the neighborhood of $3 million a year just in end-stage renal services. So this is an example of cost savings that could be realized if we had adequate prevention of this particular disease.

I would like to close my statement by saying that I appreciate the committee's wisdom in initiating this legislation, and I feel that it will go a long way in making it possible for prevention of diabetes and reduction of costs associated with diabetes. Thank you.

[Prepared statement of Dr. Johnson appears in the appendix.]

The CHAIRMAN. Thank you very much for an excellent statement.

Senator Inouye.

Senator INOUYE. Thank you very much.

Is there any screening program available in the State of Hawaii at this moment?

Dr. JOHNSON. Yes; there is, sir. The American Diabetes Association, in conjunction with the State Department of Health, have been doing screening for a number of years; 1985 was the first year in which they collaborated on their screening. However, it is done on an ad hoc basis and does not cover the entire State each year.

Senator INOUYE. Is it available to all?

Dr. JOHNSON. Yes; it's available to all groups, and Hawaiians are found to participate in the screening at a lower rate than other population in the State.

Senator INOUYE. Does the correlation that you have found with the disease and lower income and rural residences apply to the total native American population, including Indians?

Dr. JOHNSON. Yes; I believe it's the same, sir.

Senator INOUYE. What would you suggest that the moneys be used for?

Dr. JOHNSON. In diabetes, I think initially, as the legislation indicates, there has to be additional research into the nature of diabetes and targeting specific groups. We don't know, for example, how many actually have diabetes in the State, and I think that this would be an excellent way to begin. Also, in addition to that, we need to have adequate planning, and we need to have the community, the Hawaiian community, activated in this planning and awareness through educational programs of the seriousness of the disease.

Senator INOUYE. Mr. Kanahele.

Mr. KANAHELE. Yes, sir.

Senator INOUYE. What role do you believe OHA will be playing if this measure should pass?

Mr. KANAHELE. I think being the lead agency for all Hawaiians and native Hawaiians in the State, our most important position is to bring the native Hawaiians around to accept the new educational experiences in this field, which is something that Hawaiians are not used to. I think our access to all of our Hawaiian people, which no other State agency and/or organization in the State has, would be perhaps the single most important directive that this agency could do in cooperating with this new effort.

It is most important simply because, of our population, the native Hawaiian suffers the most in this area, and the office who has the last word in everything with regard to the future health of all native Hawaiians can benefit most by doing so.

Senator INOUYE. Is your organization geared to do this at the present time?

Mr. KANAHELE. Our organization is in the process of beginning to direct this offer, and, yes, we will be working with many, many other native Hawaiian organizations such as the Hawaiian civic clubs in the State, and we are prepared for it.

Senator INOUYE. Thank you very much, sir.

Mr. KANAHELE. [Inaudible.]

The CHAIRMAN. Thank you very much, Senator.

Thank you both very much.

Our next panel will be made up of Reba Walker, who is representing Alyce Spotted Bear, who is the chairman of the Fort Berthold Tribal Business Council. Alyce is tied up in North Dakota with about 14 inches of snow. Reservation roads aren't all that good.

Caleb Shields, a member of the Tribal Executive Board of Fort Peck Reservation; and John Buffalohorn, who is the president of the Northern Cheyenne Tribe from Lame Deer, MT.

Pull up another chair over there, John.

Let me finish my brief opening statement, and without objection, we will put it back where it would have been had I continued it, out of deference to our Senate colleagues who were here to testify.

What I was pointing out was that, my God, what can be more priority than to get a death rate down from 12 times the national norm to closer to normal. I mean, if this doesn't cry out for attention, I don't know what does. It seems to me the statistics alone would indicate that whatever the IHS is currently doing to address the problem of diabetes, that effort needs to be supplemented and expanded.

S. 1988 provides for the expansion of existing IHS model diabetes clinics and authorizes research on diabetes and its associated complications, as well as outreach activities to educate the native communities in the prevention and control of diabetes. I believe this legislation is needed. I strongly support it.

It is not spending legislation, it's an investment program. And if people don't care about human beings and their fellow mortals and only worship the dollars, they still should be for it because it's going to save $10 to $12 in health care costs and the rest down the line if you address it upfront. That's why it's an important program.

Senator Melcher, do you have an opening statement?

STATEMENT OF HON. JOHN MELCHER, U.S. SENATOR FROM MONTANA, AND MEMBER, SENATE SELECT COMMITTEE ON INDIAN AFFAIRS

Senator MELCHER. I want to say that, first of all, this bill is going to establish a program to find out how much diabetes there is among native Americans and then to map out a program of education, prevention, and finally, treatment. Now, all are needed, so the bill is needed. We have no idea how many native Americans have diabetes. We are very limited in our knowledge, and we want to overcome that limitation on knowledge. We have no idea why native Americans have an incidence of diabetes many times higher than the rest of the population, and we want to know.

Now, there is going to be money for whatever is needed out of IHS. IHS is going to testify that the bill isn't needed; that they're doing this and they're doing that. Well, that's fine. But doing this and that hasn't even begun to answer the basic question. IHS is going to say, well, we don't have the means to do much more because there's a lack of funds. Well, I would just say to IHS, even before they testify, that we're going to shake the tree, this tree here in Washington, and we're going to find some funds, either in a cooperative way where IHS works with us or in a noncooperative way where IHS continues to be reluctant and recalcitrant.

So the simple fact is that today marks the official proceeding by this official hearing on this official bill to do what we should have done years ago to start the process, to find out how much incidence there is, to find out how to tell people about it that are affected in the native American community, to find out how to prevent it, and then, how to treat this very serious problem.

That's all I have to say, except to urge that we start on it. The committee has been preparing this legislation for almost a year now. It may seem like a slow start, and it is, but I'll tell you it will continue until we establish a diabetes program for native Americans.

[Prepared statement of Senator Melcher appears in the appendix.]

Senator MELCHER. Mr. Chairman, I ask unanimous consent that at this point in the record there be included a memorandum from Dr. De Ortube to myself, dated April 14, 1986, setting forth the details of S. 1988.

Additionally, I request that a copy of the Congressional Budget Office report on S. 1988 also be included at this point in the record.

The CHAIRMAN. Thank you very much, Senator. And without objection, it is so ordered.

[Material referred to appears in the appendix.]

The CHAIRMAN. As Senator Melcher points out, we are indeed making our beginning here, and your testimony is going to help a great deal because when we take this bill to the floor, the testimony that you present, tied in with the statistics we're able to get, will give us the background information we need to build a strong case for the bill on the floor. That's why you're here today. We need as much information as we can possible get.

I would now like to recognize Reba Walker, who is speaking for Alyce Spotted Bear, the chairman of our Fort Berthold Tribal Business Council.

Reba, good to have you here again.

Ms. WALKER. Thank you.

The CHAIRMAN. Let me assure you that your testimony will appear in its entirety in the record if you want to summarize. We would be glad to have your testimony.

STATEMENT OF REBA WALKER, REPRESENTING ALYCE SPOTTED BEAR, CHAIRMAN, FORT BERTHOLD TRIBAL BUSINESS COUNCIL

Ms. WALKER. Thank you very much. I am sorry that Alyce Spotted Bear couldn't be here. As you know, we had a terrible snowstorm in North Dakota and there were 15 inches of snow when I left there.

My name is Reba Walker. I am a member of the Mandan and Hidasa Tribes, and I am a professional nurse. I am on leave today from my position as the health center director for Indian Health Service, with the full knowledge of the area director, Dr. Terry Sloan. He has agreed that I could make my statement today based on my professional knowledge.

I will just summarize what I have as a prepared statement that has been submitted.

First of all, I think it's important to look at incidence and look at it in terms of what is happening on the northern plains. I would like to compare the death rates for two periods: from 1974–77, and 1981–83.

The incidence between 1975 and 1977 on Fort Berthold was 51.7 per 100,000 population. In 1981–83 it was 123.8 per 100,000 population. For that same period, for the Aberdeen area in 1975–77, the incidence was 32.3 per 100,000 population; then in 1981–83 it was 51.3.

So you can see there has been a drastic increase, probably the most drastic at Fort Berthold, and also a drastic increase for the Aberdeen area. However, for Indians in the Nation, the incidence in 1975–77 was 20.1 per 100,000 population, and in 1981–83 it was 19.9 per 100,000 population. So that says to me that if you remove those reservations that have the high incidence of diabetes—Pima, Papago, and others, and Fort Berthold and most of the Aberdeen area—the incidence would be much lower for the overall Indian population.

The incidence, the known incidence, at Fort Berthold is 31 percent for the adult population—that is, the population over 40 years of age. There are many, many borderline diabetics there, and it's safe to assume that were all diabetics known on that reservation, that would be about 50 percent of the over-50 population.

Another indicator for diabetes is obesity. The majority of the adult population on Fort Berthold is obese. The complications of diabetes are many on Fort Berthold. Nephropathy, or end-stage renal disease, we have had this year two deaths. We have about 6 who are on dialysis and 12 who will be within the next 12 months. We have a number of people who have immuno-suppressed conditions; those are people who had kidney transplants and because of those

transplants have low resistance to viral and bacterial infections, and so maintaining those people is a costly, difficult situation in terms of health management.

We have loss of extremities occurring at all times. This is caused by the reduced-circulation problems, as well as neuropathy. Neuropathy is sensory deficit, and when that sensory deficit occurs in the extremities, people get burned easily, if they step on a tack they don't know it. Then sores develop and eventually their limbs are lost.

Fort Berthold does not have a hospital. It's an ambulatory-care situation. About seven hospitals are used around the reservation. It's difficult to control that situation because many times inappropriate treatments are used. For instance, it's really dangerous to soak the feet of people who have sores, who are diabetic, but this has occurred.

We have diabetic clinics in all of the communities, and they are usually staffed by health educator and community health nurses. We have needs for podiatrists, a full-time nutritionist, an endocrinologist, as well as—I guess I said nutritionist.

In terms of prevention, we need a considered effort to reduce the incidence of obesity, and that need is for a program that begins at a very early age and impacts all age groups on the reservation.

Another problem is that many of the people who are diabetic receive commodities because of eligibility. Commodities are high in fat, they're high in—they have pork and chopped beef and butter and lard. Those are all—they all contribute to the incidence of diabetes.

If you look at the WIC Program, WIC is selective about those, the foods that are used in that program. And it seems to me that if we are going to do anything about diabetes, then the commodities program needs to be revised and a reduction in the fat content and the salt content of those foods is critical because any education program cannot be implemented unless the nutritional elements of the foods available to people are adequate and reduce those nutrients that are really not nutrients but dangerous to individuals.

Fort Berthold Tribal Business Council requests that a model project be implemented on Fort Berthold and that there be a training of outreach workers who are community health representatives as well as community health nurses to impact this problem which is probably the most acute in the Nation.

That concludes my statement.

The CHAIRMAN. Thank you very much for an excellent statement.

In testimony before this committee, the administration's fiscal year 1986 budget, the three affiliated tribes indicated that the Indian population at the Fort Berthold Reservation was 3,500 in 1987. Does this represent the entire service population for IHS services at Fort Berthold, or are there additional offreservation members who also receive services?

Ms. WALKER. The population, which includes Ward County, would be over 4,000.

The CHAIRMAN. Would be over 4,000. Now, in fiscal year 1984 the tribes received a small grant from IHS to provide, among other things, for screening for diabetes at health fairs. How many tribal

members have been identified as having a diabetic condition as a result of these health fairs?

Ms. WALKER. I don't have that data.

The CHAIRMAN. Could you provide that for the record?

Ms. WALKER. Yes; I will.

[Material to be supplied appears in the appendix.]

The CHAIRMAN. Now, you mentioned a model project that, in essence, is a proposal for treating and controlling diabetes at Fort Berthold. Have you developed a cost projection for implementing this proposal?

Ms. WALKER. No; we have not.

The CHAIRMAN. Could you give us an estimate of what it would cost?

Ms. WALKER. $50,000.

The CHAIRMAN. A year?

Ms. WALKER. Approximately.

The CHAIRMAN. And what would it do? Mainly diagnose, or would it be largely related to treatment and prevention?

Ms. WALKER. It would do two things. There would be an element of prevention that I think is most critical. And second, a treatment program which would include such services as a podiatrist, a nutritionist, and an endocrinologist—and most importantly, a full-time nutritionist.

The CHAIRMAN. In other words, largely related to nutrition and prevention so that we don't have these staggering statistics.

Ms. WALKER. Yes; and assistance with treatment, since physicians at Fort Berthold, having recently finished their residency, could use assistance and direction.

The CHAIRMAN. Thank you very much.

Senator Melcher.

Senator MELCHER. I have no question.

The CHAIRMAN. Thank you.

Our next witness will be Caleb Shields, who is a member of the tribal executive board at Fort Peck Reservation, Poplar, MT. I have a hearing that I am to go to. I leave the next panel to Senator Melcher.

Senator MELCHER [presiding]. Please go ahead.

The CHAIRMAN. Proceed, Mr. Shields.

STATEMENT OF CALEB SHIELDS, MEMBER, TRIBAL EXECUTIVE BOARD, FORT PECK RESERVATION, POPLAR, MT

Mr. SHIELDS. Thank you, Mr. Chairman. My name is Caleb Shields, of the Tribal Council for Fort Peck. Accompanying me in the audience is Kenny Smoke, who is also a member of the executive board and chairman of our tribal health board.

Next to the abuse of alcohol, diabetes is Fort Peck's No. 1 health problem. Diabetes shortens lives and can cause blindness, loss of limbs, and other serious disabilities. The high incidence of alcoholism increases the problems with diabetes because alcoholic diabetics frequently do not control their diets, monitor their blood sugar levels, and take the proper medication.

Diabetes is also a very expensive problem. It puts a tremendous strain on every component of the Indian Health Service and tribal

health budgets. To give just one example, we have 15 diabetics on the reservation who need kidney dialysis. This number has more than doubled over the past 2 years, and Medicare bears a portion of this cost and the tribes pick up the rest, including needed support services. Over the past 3 years, the Fort Peck tribes have spent $192,000 on kidney dialysis and related services.

The Fort Peck tribes believe that this terrible situation could be significantly improved through an expanded Federal program to combat diabetes. The tribes, therefore, strongly support S. 1988, and the tribes thank Senator Melcher and the other sponsors of the bill for introducing this much needed legislation.

The bill takes a comprehensive approach to the problem of diabetes, and it seeks to improve research and data collection as well as prevention and treatment.

There are several portions of the bill for which we would like to express particular support. Diabetes is an excellent target for health promotion and disease prevention efforts. Even difficult cases can often be controlled through diet, monitoring, and other health promotion efforts. Borderline cases can essentially be prevented altogether, and through proper education, potentially diabetic young people can develop the habits early in life that will avoid severe problems later on.

Given these facts, we strongly support sections 4, subsections (a)(3), (a)(5), and (a)(6) of the bill. These sections would require Indian Health Service to train Federal and tribal health care providers in diabetes prevention and control, develop health education materials on diabetes for Indian communities and schools, and provide proper followup care for Indian diabetics.

These programs will help control severe cases of diabetes and stop other cases before they get started. They will also save money in the long run because prevention is much less expensive than hospitalization and other forms of direct medical treatment.

We at Fort Peck have heard excellent reports concerning the IHS model diabetes programs. We therefore support section 4, subsections (c)(1) and (c)(2) of the bill, which would continue the existing programs and require IHS to establish five more such programs, including one in Montana.

However, even more important is section 4(c)(3), which would require Indian Health Service to assure that the knowledge and benefits gained from the existing model diabetes program be made available to all service units. IHS has enough experience with these model programs by now that the diabetic program at every service unit should be similar to the model program.

I would like to express two concerns about the bill. First, it is Indian people who suffer from this terrible disease in such high numbers, and we believe we have a unique knowledge of diabetes and social problems that make control of this disease so difficult.

The Fort Peck tribes therefore request that in undertaking the activities required by section 4 of the bill, IHS be required to consult with tribes and tribal health contractors to take into account tribal-specific health plans. And we attach to this testimony language that would accomplish this change.

S. 1988 would add native Hawaiians to the Indian Health Service population for purposes of diabetes programs. To the extent that di-

abetes is a severe problem for native Hawaiians, the Fort Peck tribes support Federal assistance for this group. However, we are also concerned about placing additional stress on IHS, which already has limited resources. As a compromise, we suggest that native Hawaiians be deleted from this bill and that their needs with respect to diabetes be addressed within S. 2243, the Hawaiian-specific health bill.

Finally, I would like to say a few words about the administration's position on this bill. The administration opposes the bill, in part, because it might result in deductions from funds from other higher priority activities. The tribes find it difficult to believe that there are activities of higher priority than prevention, control, and treatment of diabetes. And even if S. 1988 would require diversion of funds from other programs at current funding levels, the IHS response should be to request more funds. This would be a welcome change from the outrageous cuts that the administration requests every fiscal year.

That concludes the written testimony on S. 1988, Mr. Chairman. I would like to add some comments.

We at Fort Peck do have a diabetic clinic, but the statistics that we have compiled for the most part are incomplete and inconclusive of the exact numbers of diabetes cases on Fort Peck. We have a service population of around 5,855 Indians on the reservation, and our statistics show that 92 or 93 percent of those who have diabetes are in the age group of 35 years and older. We are finding that complications from diabetes range from those who are suffering from diabetes have the complications of high blood pressure, which is around 48 percent of our diabetics, following with amputees and nerve-damaged clients.

We would like to have the record left open until we have our final statistics compiled, and we will submit them for the record.

Senator MELCHER. Without objection, the record will be left open for the hearing for 30 days. That may not be long enough, Caleb, but that's as long as we can leave the record open.

Mr. SHIELDS. Yes; on my own, Mr. Chairman, I have talked to different groups. Taking my family as an example, there are 10 in my family, including the father and mother. Thirty percent of the 10 have diabetes. I have talked with other family sizes that range from 9 to 10, and each time I am finding that at least three or four of their family members have diabetes.

Our records at Ford Peck do not show a high rate of diabetes, but our records only show, I believe, severe cases, severe cases of diabetes. I think what we're experiencing at Fort Peck is, until a person becomes very, very ill, say, from a heart problem or high blood pressure, that he goes in for that particular reason and then they check him out and then they find out he also has diabetes. It's not until they go in for some other purpose do we find diabetes associated with that illness.

So I think with the new figures that we're going to be coming up with, it's going to show other than what we have today, it would be a high rate of diabetes.

[Prepared statement of Mr. Shields appears in the appendix.]

Senator MELCHER. Thank you very much, Caleb.

John Buffalohorn, president of the Northern Cheyenne Tribes.

STATEMENT OF JOHN BUFFALOHORN, PRESIDENT, NORTHERN CHEYENNE TRIBE, LAME DEER, MT

Mr. BUFFALOHORN. Thank you, Senator Melcher. I want to thank the other members of the committee for the opportunity to present this testimony on behalf of my tribe, the Northern Cheyenne Indians of Montana, and also to express our support for S. 1988.

I am submitting a written testimony for the record.

Senator MELCHER. The written testimony will be printed in its entirety.

Mr. BUFFALOHORN. All right. We have been fighting the effects of diabetes on the Northern Cheyenne Reservation for the past 6 years. Just briefly, I would like to outline some of our efforts.

Prior to 1980, there were no organized efforts in the treatment and prevention of diabetes and dialysis on the reservation. Statistical data in the prevention of diabetes were sketchy and almost nonexistent. There were patients diagnosed and 1 patient was receiving treatment for dialysis.

In 1983, a diabetic clinic in Beckhurst was formulated to help with monitoring and treatment for diabetes. This clinic is conducted once a month and is not adequate to meet the needs of our people.

Two years ago, the home dialysis program was founded and housed in Lame Deer. Local people who speak the Cheyenne language were trained for 6 weeks at Deaconess Hospital in Billings. The Northern Cheyenne Tribe is the primary funding source. However, future resources for the tribe look bleak. The program although drastically needed, may not continue in its present location. S. 1988 will help to alleviate this problem.

At present, there are 135 diagnosed diabetics who are active in our diabetes treatment program. Five people receiving dialysis treatment, four are diabetic, three more are being prepared for treatment. There are 26 diabetics that have nerve damage and are possible candidates for dialysis.

A year ago, a proposal for assessing and changing services was submitted and funded. That was in January. The IDS began and could lead to a more modern program with proper staffing and resources.

In the future, we feel that to work toward prevention, we must alter the susceptibility for the Northern Cheyenne people. This can be done through education and active involvement in the health care system, and finally, the behavior changes by altering the individual and group lifestyles, taking into consideration major cultural aspects of the Northern Cheyenne people.

The people who are most susceptible need to be identified and worked with prior to the onset of the symptoms of the disease. Some of you knew and worked with the late Mr. Allen Rowland. For those of you who did not, Mr. Rowland served the Northern Cheyenne Tribe as an elected official for two decades—4 years as a councilman and 16 years as a president of the tribal council. Mr. Allen Rowland was a victim of diabetes.

During that tenure, he established himself as a great leader in the Indian country. One major accomplishment in the area of Indian health care was the establishment of the Northern Chey-

enne home dialysis program. Unfortunately, Mr. Rowland died at the age of 59 due to end-stage renal disease.

A quote from a tribute written after his death in February 1986 reads:

> Allen's death leaves the seat empty at the negotiating table. But his work is not done, and the progress he set in motion must continue. It is up to us to carry the burden he shouldered for so well and so long to improve the lives of Indian people and to preserve their resources and culture. Allen Rowland was both a great native American and a great American.

In a larger sense, Allen Rowland shows all of us how to develop cooperation between Indian and non-Indian, and he convinced us that joint progress in our interests was in the best interests of Montana and the Nation. Once again, all native Americans must face another battle, this battle being against diabetes.

The passage of this bill will allow all native Americans to have a fighting chance. We realize the importance of the committee's support of S. 1988 and are grateful for it.

In conclusion, I want to thank Senator Melcher and his colleagues in supporting this bill. We are very thankful for the opportunity to express our support for the bill.

[Prepared statement of Mr. Buffalohorn appears in the appendix.]

Senator MELCHER. Thank you very much, John.

Now, without objection, immediately after the statement of the chairman, Senator Andrews, my opening remarks will be made part of the record.

Immediately after my opening remarks, without objection, the memorandum from Dr. De Ortube, a professional staff member of the committee, will be made part of the record. The memorandum is dated April 14, 1986, and it gives a background of S. 1988 in detail.

Immediately after that, without objection, printed in the record will be the Congressional Budget Office report on S. 1988.

I might make two explanations on this. First of all, almost 1 year ago, the Indian Affairs Committee of the Senate hired Dr. Luis De Ortube, a physician of some experience, to become a member of this staff, with the assigned duty of determining, as much as possible, the amount of knowledge that is available, statistics that are available on diabetes among native Americans.

Further, Dr. De Ortube was assigned to be in consultation with tribes across the country and in consultation with native Hawaiians.

He has done that. He has made a couple of field investigations to view what IHS is doing about diabetes and also to learn what isn't being done about diabetes for native Americans.

As to the Congressional Budget Office report, it has a modest amount estimated for outlays ranging from $5 million per year for fiscal year 1987 to $6.7 million for fiscal year 1990–91. We repeat that for our hearing, and it will be part of the record.

We want to thank you, Alyce, Caleb, and John for your testimony. Due to the uncertainty of the time, the committee will have to be in recess at this point until Senator Burdick or another member of the committee can be present to receive further testimony.

The committee is in recess, subject to the call of the Chair.

[Recess.]

Senator BURDICK. Our next witness will be Arta Carlow, chairperson, Oglala Sioux Tribal Health Authority, Pine Ridge. Is the witness here?

[Pause.]

STATEMENT OF ARTA CARLOW, CHAIRPERSON, OGLALA SIOUX TRIBAL HEALTH AUTHORITY, PINE RIDGE, SD

Ms. CARLOW. My name is Arta Carlow. I am an Oglala Sioux from Pine Ridge, SD. First of all, I would like to thank you for being able to attend this, and we support that bill very much. We think it is a very good bill, and we are happy to be able to support it.

I would just like to say few things. We have turned in our written testimony, but there are a few things that I would like to add to it. We have a lot of diabetics. I can't give you the exact number today. But we have diabetic clinic twice a week at our hospital, and once every 2 weeks one of our doctors gets with the diabetics that are able to attend the meeting, and he kind of educates them to their diet and their problems that they have.

And there is another thing that we need real bad is our people don't have water. We don't have inside water. And there is a—we have quite a few amputations, and not being able to take care of their sores and whatever, it goes on to amputation. And we have dialysis program, and we have seven patients that take the treatment at the present time, and we're getting more of them just from being a diabetic.

We don't know what causes all of our diabetics, and this bill would really help us. And we have our people that are getting commodities, and at one time they thought it was probably the food that they were getting because they have so much starch food. But that is something that we don't know either.

But we are really in need of water for our people to take care of their health, which helps the diabetic people with their problems.

We have turned in our written statement, and I think we have everything on that. But I just wanted to bring up, like, the water and that we're getting more diabetics every day, and there is some of them that we don't even know about because they don't come to the hospital. But we're encouraging them to come all the time. So that is some of our problems.

But we have diabetic people that are losing their eyesight; amputations, and kidney problems and having to go on to dialysis.

[Prepared statement of Ms. Carlow appears in the appendix.]

Senator BURDICK. Your full statement will be made part of the record.

Ms. CARLOW. Yes.

Senator BURDICK. I have just one or two questions.

Ms. CARLOW. Yes.

Senator BURDICK. What recommendations do you have for improving the diabetic program on the Ogalala Reservation? Would open IHS clinics used more frequently be of any help? Would adequate staffing with expertise in diabetic treatment?

Ms. CARLOW. Yes.

Senator BURDICK. Or improved transportation for rurally isolated communities? Or all three? What do you think is most important?

Ms. CARLOW. We do have a transportation problem, too, getting our people to the hospital because they just don't have a way to get there, and there's where we use the CHR's a lot to bring in our patients.

Senator BURDICK. I have been told—I am not a medical expert—but I have been told that much of the problem originates in the diet.

Ms. CARLOW. That's what——

Senator BURDICK. Is there anything that can be done with the young people of school age on up to kind of supervise their diet? Is there any way that could be done, through the school administration some way?

Ms. CARLOW. It probably would be good if they'd have more education on it. But, see, we have so many low-income people that, you know, it's hard to get the foods that they really need to have.

Senator BURDICK. I know the problem of income, of course. But sometimes you can do a little better job with the income you have if you use your limited funds for the right food. I was just wondering if diet itself might be helpful.

Ms. CARLOW. Well, I think so.

Senator BURDICK. What do you recommend be done in the local schools for education and prevention? What part would schools play in this?

Ms. CARLOW. Well, I think teaching the children the right foods that they should have.

Senator BURDICK. Are they teaching things like nutrition now in the grade schools, for example?

Ms. CARLOW. Not really.

Senator BURDICK. It seems to me that's quite an opportunity to do something about the diet, start right there in the grade schools.

Ms. CARLOW. Well, I do, too, but I don't think it's being done.

Senator BURDICK. Well, thank you very much for your contribution.

Ms. CARLOW. OK. Well, I would like to thank you again for being here and being able to testify. Thank you.

Senator BURDICK. Out next witness will be Viola Johnson, director of the human resources department, Gila River Indian Community of Sacaton, AZ.

Ms. JOHNSON. Yes; that's right. Sacaton.

STATEMENT OF VIOLA JOHNSON, DIRECTOR, HUMAN RESOURCES DEPARTMENT, GILA RIVER INDIAN COMMUNITY, SACATON, AZ

Ms. JOHNSON. Good morning. Gila River Indian Community is located 30 miles south of Phoenix in Arizona. The community is composed of Pima and Maricopa Indian Tribes. There are approximately 10,500 members enrolled in the community, with about 7,000 residing on Gila River.

I thank you for this opportunity to testify regarding S. 1988, the bill to establish programs for the prevention and control of diabetes among native Americans. Unfortunately, it appears that Pimas

and Maricopas are particularly susceptible to this disease and the impact of diabetes on individual tribal members and their families has been and is disastrous.

This committee should look to the statistics prepared and development by the Indian Health Service relating to the physical health of Pimas and Maricopas, and attempt to measure the impact of the disease on the social and cultural life of tribal members. In this statement I shall relate to you how diabetes has affected the people of my reservation, what is being done about it, and what needs to be done about it as I see it.

Diabetes is a new disease for our people. As early as 1937 its incidence was rare on Gila River. It was in the 1930's that the change in the lifestyle of Pimas was apparent. By this time, Gila River had become dry because of the upstream diversions of water by non-Indian settlers, which began shortly after the Civil War. The effect of these diversions was to destroy the economic base of Pimas and Maricopas, which was primarily based agricultural. Crops withered and cattle perished. We adopted the diet and ways of white men, which has not been good for members of Gila River.

Because of the efforts of NIH on our reservations, we know that half of the people over 35 have diabetes. If you were to ask a young Pima if they have diabetes, their answer will often be, "No, not yet." Becoming diabetic goes beyond the fear that the people have; it is reality. We have become fatalistic in our view of the future.

I think it is difficult for a young person to have a healthy outlook on life when both their mother and father have diabetes, their aunts and uncles have legs amputated or are blind, and a grandmother has died of kidney failure. The question is not if but when I will get diabetes.

What is being done about diabetes in Gila River? In 1984, 13 percent of all the outpatient visits, 5,300 for the Sacaton Hospital and to the diabetes model project were for diabetes care. The success of this treatment can be measured in the numbers of complications our people endure. Unfortunately, we do not currently know how many community members are blind or how many hae amputations because of diabetes, but both are common.

However, we do know how many people have kidney failure. Out of a total of a population of 10,500, we currently have 48 tribal members on dialysis. Five more will be added to the group within the next couple of months. The cost of dialysis, including transportation, is $2,550,000 a year. Yet this number will only increase as tribal members are put on dialysis and the survival rate increases because of improved technology.

Much effort and money is being spent on treating the disease. The new Sacaton Hospital will soon be under construction, and with the anticipated improvement of the delivery of health services upon completion, attention must be focused on improved diabetes prevent in programs. But unless sufficient moneys are appropriated to finish construction for the hospital, efforts to prevent and control diabetes at the Gila River may not be as effective as they should be.

What is being done to prevent diabetes from occurring in the first place? Indian Health Service funds no prevention programs at Gila River directly. Approximately 4 hours of staff per week from

the diabetes model project is devoted to the tribal prevention project called the St. Peter's project. This project addresses overweight children and encourages family participation in becoming physically fit.

For a project startup budget of approximately $60,000 and a maintenance budget of only $35,000, it has the potential to prevent diabetes. Early results show that the rate of weight gain in third- and fourth-graders at St. Peters has been slowed. And the community knows from the NIH that obesity leads to diabetes. The St. Peter's project is one innovative approach being tried by our tribal program working together with the diabetes model project.

Contrast the $2,550,000 spent on dialysis with $60,000 spent on prevention programs. There must be more emphasis on prevention of diabetes. It is certainly cost effective to adequately fund prevention programs rather than to save the astronomical cost of treatment in the future.

How can we turn this around? Funding and developing innovative programs I think is the answer.

I shall now comment on specific provisions of S. 1988. In the findings and purpose part, section 2(a)(5) (b) and (c) and section 2(b)(2) are especially important. There must be, clearly, diagnosis, early diagnosis and prevention programs developed. It is also clear to me that the prime factor in preventing diabetes is the proper training of native Americans health care providers. Unless what is known about diabetes is translated into specific action on the reservations, it is difficult to control diabetes.

I am in general agreement with the diabetes care program outlined in section 4. And as previously stated, training programs for native American health care providers must be funded.

Health education efforts regarding prevention must also reach the classrooms in our schools. Our St. Peter's project is an example of how collaboration and cooperation can succeed. There must be more emphasis on joint projects involving tribal, Federal, and State funds.

I thank you for listening to how diabetes has affected Gila River. This concludes the testimony.

Senator BURDICK. Thank you.

I understand that there is an extremely high prevalence of hypertension on the Gila River lands not common to other tribes. Is that correct?

Ms. JOHNSON. Yes; this is true, Senator.

Senator BURDICK. Can you give me a reason why that is true?

Ms. JOHNSON. Hypertension can be directly linked to being overweight. Gila River participated in a State blood pressure screening program a few years ago. Approximately 10 percent of the people were identified as having high blood pressure. Many were also diabetic and did not attend clinic regularly. Again overweight is a contributing factor. Diet and sedentary lifestyle are also causes. What we eat and how we prepare our food is different.

Senator BURDICK. When you get right down to it, diet causes a lot of disease.

Ms. JOHNSON. That's right, as adults we know that poor eating habits are difficult to change. Good eating habits must be formed early in life.

Senator BURDICK. One section of the bill is very good—page 6, sub (5). The purpose of the bill is to develop and present health education information to native American communities and schools concerning the prevention, treatment, and control of diabetes. I think that would probably do more than anything I can think of is to have a thorough education program for the disease. I think it would be helpful starting early in the grade schools.

Ms. JOHNSON. This is true. On Gila River we have demonstrated that it is possible to teach children good eating habits and the importance of exercise. The St. Peter's project is a small group of children. There were only 21 children in the study. After 1 year third- and fourth-grade students maintained their weight, exercised regularly, and learned what foods were good for them. We must emphasize education and prevention of disease. Health providers have this responsibility; we can't wait until people get diabetes. We have to start teaching early on, and early on means primary grades. You and I know that once we develop bad habits, they are difficult to change. This includes eating and lifestyle.

Senator BURDICK. We also know that people without too much money have a tendency to fill up their stomachs with starch.

Ms. JOHNSON. Yes; I suppose this is true.

Senator BURDICK. Breads and so forth. They don't have a balanced meal. I know that that's to some degree based upon their income, the money they have available. Even so, they could be selective in their foods. A little education along that line would help a lot, I think. When you get right down to basics here, it's the diet.

Ms. JOHNSON. Yes; on Gila River we have a commodity food program. A major goal is education in how to use the food, to provide a well-balanced diet.

Senator BURDICK. Well, my next question you have more or less answered. What can be done to combat that diabetes? I guess the main question is diet and early detection.

Ms. JOHNSON. Yes; I think early detection is important but even before that, I think, it's the education. We strongly support education programs for the children in our schools. We're a young population. Approximately 42 percent of the population is under the age of 19. That's a large number of school-age children. At present most of our programs are treatment oriented. We provide secondary and tertiary care because this is what we are staffed to do. What we need is a change in our focus. This will require additional funds for a comprehensive health education program in our schools.

Senator BURDICK. Well, I thank you for your testimony. It was very helpful.

Ms. JOHNSON. You are welcome.

Senator BURDICK. Don LaPointe, a member of the National Indian Health Board executive committee, of Denver. Is he present?

I wonder if you could summarize your statement, in the interest of time.

Mr. LAPOINTE. I will do that, yes, in the interest of time.

STATEMENT OF DON LaPOINTE, MEMBER, NATIONAL INDIAN HEALTH BOARD, EXECUTIVE COMMITTEE, DENVER, CO

Mr. LAPOINTE. My name is Don LaPointe. I am a board member of NIHB, and I have been for the last 14 years. I am also vice chairman of the Keewenaw Bay Tribal Council in Baraga, MI, and I am also their chief executive officer for the tribe. I am a diabetic.

The funding for preventive medicine within Indian Health Service has not been sufficiently addressed in the past years. The shortage of funds has not allowed model diabetic clinics currently in existence to expand into other clinical settings. S. 1988 also addresses this issue. Proper funding must be assured in order to expand this service.

The NIHB is concerned over the inclusion of native Hawaiians in the services provided by Indian Health Service. We recognize that the native Hawaiian population also has genetic tendencies toward diabetes and should be provided some Federal services, but those services should be provided through agencies other than Indian Health Service.

We are fearful that any expansion of the mandated American Indians and Alaskan Natives will be diminished if native Hawaiians were included. Therefore, if the Hawaiians should be retained in the bill, we highly recommend that Congress provide special funding to meet their needs and not extract any funds from the Indian Health Service for American Indians and Alaskan Natives.

Finally, the National Indian Health Board has been informed that the administration opposes S. 1988. We understand that the administration will claim that it's already meeting this need. We disagree with any statement that may be provided by Indian Health Service that it is meeting the needs of American Indians and Alaskan Natives when it comes to providing either prevention or treatment for diabetes. They do not have the money to meet the growing need, not when experience has shown that they are only meeting some 40 percent of the total identified unmet health needs. Any type of piecemeal approach is not sufficient to meet any need, particularly when the difference is expressed in life-and-death figures.

This concludes my summary.

[Prepared statement of Mr. LaPointe appears in the appendix.]

Senator BURDICK. Thank you very much.

Mr. LAPOINTE. You're welcome.

Senator BURDICK. Given the prevalence of diabetes in the Indian population, what are the recommendations of the National Indian Health Board for the prevention and control of the disease?

Mr. LAPOINTE. That, like you stated a few minutes ago, that education along the lines of prevention would provide funding to expand the services that are available in teaching the American Indians and Alaskan Natives to care for themselves in bringing their educational level up in regard to treatment of diabetes.

That's not presently available. I speak from my own personal experience. I have had diabetes. The onset was 7 years ago, and I was aware that diabetes is awful, but I didn't realize how it was going to affect me. When I discovered I had diabetes, it was just devastating to me because I wasn't—I wasn't aware of what it would do or

what it could do. It affects every organ in your body. I have seen in my own family, my brother passed away in December of last year from diabetes. I saw what he went through. He had a leg amputated, and his eyesight went. He was—he was near blind. It affected his heart, every organ in his body was affected. I don't want that same thing to happen to me, nor do I want this to happen to my children.

There were seven of us in our family, and of the seven children, five are diabetic. When I grew up—when I was growing up, I was just a skinny, little thing because we didn't have much on the reservation. My dad raised his own garden and sometimes got a deer, and we had fish. But we were skinny because there wasn't the food to eat. And then look at me now. [Laughter.]

This happened when I returned to the reservation. I was away from the reservation for 20 years. The year I went back I gained 100 pounds. I just bounced back and forth. I try to watch what I eat to control my diet, especially since I know that I am diabetic. Every once in a while your blood sugar goes out of kilter, and the doctor will give you more insulin. The more insulin he gives you, the more your appetite increases. So you can't win.

I mean, we need more education on how to live with our diabetes or how to prevent it from happening. You're right in saying that the diet has a lot to do with it.

Senator BURDICK. Of the witnesses that I have questioned this morning, all indicate the same thing, that we need the education.

Mr. LAPOINTE. Right.

Senator BURDICK. You can't go back when you were 6 years old and start over again, you know.

Mr. LAPOINTE. That's for sure.

Senator BURDICK. The 6-year-old can.

Mr. LAPOINTE. Yesterday, before I left home, I checked with our health department on the prevalence of diabetes on our reservation. And just in 1 program, in our nutrition program for the elderly, we have between 75 and 80 people that we serve each day in our Elderly Nutrition Program, and of that number, 42 are diabetic. So it's half the population.

Senator BURDICK. Just a minute. Can you see some benefits in distributing diet sheets or having classes on diet? We had health classes. At least, when I was in school we did. Could be have proposed diet sheets of what to eat and what not to eat? I know, of course, it's limited by the money and the funds available, but there has to be some selections that might be helpful. Would you recommend something like that in the Indian schools?

Mr. LAPOINTE. Yes, yes; but we don't all live on reservations where there are Indian schools. They're not—like, where we live, they're public schools that our Indian students are in. There are not that many boarding schools anymore.

Senator BURDICK. Well, they could be available in those schools, too, couldn't they?

Mr. LAPOINTE. Right. I'm sure. That needs to happen.

A year ago my blood sugar was acting up, just about a year ago this time. I went into the hospital, and I had been going to that doctor for 15 years. We have an Indian Health Service doctor. But this was at our county hospital that I had gone into.

When I went in there, his nurse came up—and I knew the reason I went there was because my blood sugar was high, I knew that—and I went in there, and that nurse comes screaming at me, "You know better than that. You know you've got to do something to control that sugar." But yet they don't tell you what you must do. You know, there are just certain foods that you can eat that will help you keep that sugar under control, and they don't tell you because they don't know or they're not educated along those lines.

So the health professionals, not only in the Indian Health Service or Indian clinics, have to be educated to the health professionals in your public hospitals and nurses and doctors have to be educated along these lines, too.

Senator BURDICK. Let me give you a personal example, if I may. Over 30 years ago I had an examination, physical examination, to go fly an airplane. And they discovered that I had high blood pressure. That was over 30 years ago. They put me on a diet to get away from salt and butter and things like that.

For the past 29 years I have been in perfect health, and I did it through diet. I would think that this could be attacked the same way: just avoid the sugar, avoid the starches, get as much balance as you can with the money you have.

So my suggestion is can we get a list of do's and don't's about foods to distribute among the children, particularly in the schools where they're available? Would that help?

Mr. LAPOINTE. I am sure it would help, but it needs to go deeper than that. The families have to be educated, the whole family. But it can start with the kids bringing it home.

Senator BURDICK. Well, there isn't any business that is more in a pressure cooker than being in the Senate, you know that. I have had no problem with high blood pressure since, and I did it all through diet. So I think you could think about it.

Well, I guess that is it. Thank you very much.

Mr. LAPOINTE. Thank you.

Senator BURDICK. Your statement will be made a part of the record.

Dr. Everett Rhoades, Director of the Indian Health Service, of Rockville. Proceed.

STATEMENT OF EVERETT R. RHOADES, M.D., DIRECTOR, INDIAN HEALTH SERVICE, ACCOMPANIED BY DOROTHY GOHDES, M.D., DIRECTOR, INDIAN HEALTH SERVICE DIABETES PROGRAM; BRUCE LEONARD, PUBLIC HEALTH EDUCATOR, INDIAN HEALTH SERVICE; PETER BENNETT, M.D., CHIEF, PHOENIX EPIDEMIOLOGY AND CLINICAL RESEARCH BRANCH, NATIONAL INSTITUTES OF HEALTH

Dr. RHOADES. Mr. Burdick, I am Dr. Everett Rhoades, director of the Indian Health Service. Accompanying me today, on my immediate right, is Dr. Dorothy Gohdes, the director of the Indian Health Service Diabetes Program; on her right is Mr. Bruce Leonard, a public health educator in the Indian Health Service, at the moment on detail to a special program in the State of New Mexico; and on my left, Dr. Peter Bennett, the chief of the Phoenix Epide-

miology and Clinical Research Branch of the National Institutes of Health.

We are pleased to be here today to discuss S. 1988, the Native American Diabetes Prevention and Control Act of 1985. This bill deals with the very serious problem of diabetes in the Indian community, the incidence of which, as this committee has already heard, has been increasing in recent years.

Although diabetes can be treated and usually controlled, it is an insidious condition with serious potential consequences, including blindness, various kinds of vascular obstruction, and kidney failure.

I would like to make some general comments about diabetes, its impact upon the Indian community, and what the Indian Health Service is currently doing to address this very serious problem.

Since 1940, the incidence of diabetes, particularly what is called non-insulin-dependent diabetes—or more easily identified as type II diabetes—has increased dramatically in many tribes, although not all tribes, in the United States. The most precise data that are available are for the Pima and Maricopa Indians, largely because of the continuing longitudinal study of diabetes conducted by the National Institutes of Health, under the direction of Dr. Bennett.

In recent years, the complications of diabetes have become more frequent as the number of patients with longstanding diabetes has increased. In fiscal year 1983, 76 percent of the amputations done on the lower extremities in Indian Health Service or under contract by Indian Health Service were performed on patients who had diabetes. A comparable figure for amputations of the lower extremities in all races in the U.S. population is 50 percent.

The committee has also heard of complications of end-stage renal disease, which also is a growing problem. In the States of Arizona and New Mexico the renal failure rate for American Indians is 3.5 times greater than the rate for whites; 50 percent of Indian end-stage renal patients also have diabetes, and a comparable figure for all races in the United States is 25 percent.

The rate of first surgery for cataracts of the eye is 2.2 times higher in Pima diabetic patients compared to Pima nondiabetic patients. The rate of congenital anomalies is 3.8 percent in normal and prediabetic pregnancies compared to 19 percent in diabetic pregnancies. Further experience among the Pimas suggests that careful metabolic control of diabetic women during pregnancy improves the perinatal mortality markedly.

The age-adjusted death rate per 100,000 population for United States all races in 1982 was 9.6, and the comparable rate for American Indians residing in Indian Health Service service areas was 25.5.

The number of outpatient visits for diabetes has been steadily rising for 15 years. In fiscal year 1981, nearly 26,000 patients visited Indian Health Service facilities for diabetes. By 1984, this had risen to almost 40,000. Among the Pima Indians the prevalence of diabetes increased by 42 percent in the decade between 1967 and 1977, and there is every reason to believe that these trends will continue.

The incidence of diabetes has increased by one-third among the Pimas when comparing the years 1965 through 1974 with the years 1975 through 1984.

The Indian Health Service has in place a significant diabetes prevention and treatment program. It began in 1979 with the development of five model care sites. Since then, the program has developed along several lines. Additional model sites have been added, and several types of outreach activities have been initiated in order to improve the care and prevention of diabetes throughout Indian Health Service. The original five model projects were developed in different types of facilities in different settings, so that experience gained in the sites could be applied in a wide variety of service units. Most teams consist of nursing, nutrition, and physicians assistants, although several have physicians dedicated specifically to the prevention and treatment of diabetes.

The staff have also become heavily involved in training and technical assistance throughout the Indian Health Service. A 2-day course on diabetes in Indians was developed using faculty from major universities and the Indian Health Service program. In fiscal year 1985 there were six cooperative workships for health care professionals, involving 500 people from 16 States. Community health representative training in diabetes was initiated, and in 1985 staff were involved in 42 separate site visits in 13 States. The Winnebago service unit has a training rotation for nurses and dieticians.

Training in diabetes in the Indian Health Service has incorporated materials or faculty from the American Diabetes Association, the National Diabetes Advisory Board, and the University of Michigan Diabetes Research and Training Center.

In 1984 and 1985, service units throughout the Indian Health Service submitted proposals for seed money to improve diabetes care at their respective service units. These were reviewed and ranked by a panel of technicians, and money was distributed to the top-ranking proposals.

I would be happy to supply a listing of those projects for the record.

[Material provided in prepared statement.]

Dr. RHOADES. Diabetes control officers in nearly every area of Indian Health Service collect surveillance data about diabetes and supervise audits of care practices. Educational materials and standards of care are widely disseminated to all service units in the Indian Health Service promptly.

The headquarters diabetes program provides technical supervision for the model sites, coordinates training, and has identified barriers to care of diabetics. The headquarters program works with the National Diabetes Advisory Board, the National Diabetes Information Clearinghouse, and several other national voluntary and Federal agencies, including the Centers for Disease Control in the prevention and management of diabetes.

Picture diet manuals for Southwestern and Plains Indian foods are now available. A training package for community health representatives is under development along with other diabetes educational materials.

In summary, the Indian Health Service is directing its efforts in a substantial way toward the goals of S. 1988. I have mentioned the model sites that develop comprehensive approaches to preventive services and typical settings. The expertise in diabetes is shared through training programs and onsite technical assistance. Seed

moneys allow other service units to improve their diabetes services. Indian-oriented materials are developed and disseminated through diabetes control officers.

Current information about the extent of diabetes and its complications is collected by a diabetes control officer. Indian communities can obtain information and technical assistance from this program as needed.

It is the opinion of the administration that the authorities contained in Senate bill 1988 are not necessary to continue or improve the existing diabetes program, and in a number of instances, as has been stated earlier, could direct limited resources from higher priority activities within the Indian Health Service.

This concludes my prepared statement, Mr. Burdick. I believe that Dr. Bennett and Mr. Leonard also have statements that have been requested by the committee, following which I would be happy to answer any questions that you might have.

[Prepared statement of Dr. Rhoades appears in the appendix.]

Senator BURDICK. Dr. Bennett, proceed.

Dr. BENNETT. Thank you, Mr. Burdick. I am Dr. Peter Bennett, chief of the Phoenix Epidemiology and Clinical Research Branch of the National Institute of Diabetes, Digestive, and Kidney Diseases. I am not a direct employee of the Indian Health Service, but of course I am a member of the department. I am very pleased to have the opportunity to testify before you today about our research efforts to investigate the occurrence and causes of diabetes and its complications in native Americans.

I have a prepared statement which, with your permission, I would like to submit for the record and confine my remarks to some summarization of that statement.

Senator BURDICK. It is received for the record.

Dr. BENNETT. The activities of our institute in relation to diabetes began in 1965, when serendipitously we found that the frequency of diabetes amongst the Pima Indians was extremely high. In fact, at that time it appeared to be 10 to 15 times as frequent as in the general U.S. population.

On the basis of that discovery, and the fact that it was accompanied by seemingly the usual vascular complications of diabetes, the institute made a rapid decision to institute a longitudinal study of the Gila River population, with several purposes in mind.

Those purposes are primarily relating to identification of the causes or determinants of diabetes; the description and investigation of the natural history and pathogenesis—that is, the way diabetes develops in the community; and third, to try to identify the specific mechanisms which underlie these developments; and finally, to investigate the causes and determinants of the complications of diabetes, which include the vascular complications of which you heard some today, the complications of pregnancy and also the complications such as those affecting the teeth, for example.

The type of diabetes affecting the American Indian is almost exclusively of the non-insulin-dependent type. This is the sort of diabetes that affects about 85 percent of American diabetics in general, and more than that percentage in terms of the whole worldwide picture.

Thus, our investigations of the Pima Indians are targeted not only at trying to discover the causes and ways that diabetes progresses in the American Indian, but in the population in general.

Now, just a word or two about the complications of diabetes. You heard something about retinopathy and peripheral vascular disease which leads to amputation, and also rather a lot today about the complication of diabetic nephropathy. All of these complications which I just mentioned are, in part, a function of the duration of diabetes. They relate each to the level of hyperglycemia—that's the level of glucose in the blood. They are also each related to the blood pressure level.

The complication of nephropathy, or renal disease, I think deserves very special mention. Certainly, renal disease is relatively more frequent in the American Indian in non-insulin-dependent diabetics than it is in the remainder of the population with the disease. This is primarily, we believe, because of the relatively earlier age at which the American Indian, at least the Pima Indian, develops the disease. Typically, the age in the general population at which the disease develops is around 55 years of age. Typically, in the Pima population the age at which the disease develops is about 35 years of age.

Our studies have shown that after 20 years of diabetes, 30 percent of the Pimas develop end-stage renal disease. This means that the typical person developing diabetes at age 35 already has end-stage renal disease by the age of 55.

In the general population, end-stage renal disease, while it develops at the seemingly same rate in relation to the duration of diabetes, is not so prominent because other illnesses—cancer, heart disease, stroke, et cetera—start to take their toll in their sixties, so that only diabetics who for reasons manage to avoid those complications ultimately develop the end-stage renal disease in the population at large.

As a result of this, at this moment in time in the Pima population, end-stage renal disease is more than 15 times as common as it is in the general U.S. population. So that it does indeed represent a very, very large burden to the community.

Let me talk about some of our work in relation to the determinants of diabetes, the causes of diabetes amongst the Pimas. There is no question, I think, that the American Indian has some genetic susceptibility to develop this type of diabetes. Precisely the nature of that genetic susceptibility we do not yet know, but it does appear very likely that in the forthcoming year, using techniques that are currently available, we ought to be able to identify precisely the nature of that genetic susceptibility. If that could be done, that will represent a very major breakthrough not only for the Indian but for diabetes in general.

We also know that environmental factors play a key role in precipitating diabetes in those with this genetic susceptibility. Otherwise, diabetes would not have been rare in the American Indians before 1940. Some of those environmental factors, we have some indications about. Obesity has already been mentioned. Diminished levels of physical activity probably play a role. Excessive intake of calories, which, together with physical activity, is tied up in causing obesity. Exactly why obesity is so frequent in the American In-

dians we do not know, but our clinical research activities at the present time in Phoenix, I think, are at the forefront of research in relation to the causes of obesity, again not only in the American Indians but obesity in general.

Another determinant of diabetes which I think we shall see the increasing importance of in the forthcoming years is the fact that a diabetic woman who is pregnant, their offspring have a much greater chance of developing diabetes earlier in life than the offspring of women who only develop diabetes after they have borne their children. In fact, in the Pima, by the age of 20, 40 percent of the offsprings of diabetic pregnancies are already diabetic. This is obviously a very important finding.

What about the more basic causes of diabetes in the population? We now know that on the basis of several studies, that insulin resistance—and I will define that slightly more in a moment—plays an important precipitating and predisposing role to the decompensation or development of diabetes itself.

Our studies in relation to insulin resistance have shown that among the Pima, and presumably among other American Indians and certainly among many other people who develop non-insulin-dependent diabetes, the body's own insulin does not have the same degree of efficacy as it does in most of us. We have now gotten to the stage where we believe that that particular lesion lies within the cellular biochemistry somewhere between the state where glucose enters the cell and the formation of glycogen, which is a normal packaging product for that glucose within the cell.

We believe that a block somewhere between the entry of glucose into the cell and the formation of glycogen is at the heart of the nature and cause of insulin resistance and, therefore, of non-insulin-dependent diabetes.

We are obviously trying to work hard on this particular aspect at this time, and we indeed hope that within the very near future we shall have much more to report.

What we do know at this point are that that particular lesion appears to be inherited and might possibly be—and I will emphasize possibly—the nature of the mechanism of inheritance and the reason for the familial aggregation of diabetes itself.

In terms of the prospects for prevention, we know at the present time that people with impaired glucose tolerance—that is, glucose tolerance which is not normal but not of the degree that is diagnostic of diabetes—have a very high chance of getting diabetes in the relatively near future. We also know that glucose tolerance relates to this phenomenon of insulin resistance that I talked about already.

We know some things that influence insulin resistance. Certainly, obesity has some part. Certainly, the amount of physical activity and physical conditioning has some effect. But it appears that in order to really prevent diabetes, we need to intervene on this particular biochemical mechanism that I have alluded to.

We believe that there are opportunities to try to prevent diabetes at this time in those who have this condition of impaired glucose tolerance which antecedes diabetes in the vast majority. What we would ultimately like to be able to identify is the specific genetic susceptibility and be able to identify specific individuals who ulti-

mately, as some of our witnesses have mentioned, may be apparently normal in childhood but then go on to develop diabetes as a young adult. It is those people and those people not only among the American Indian population but in the general population that we would ultimately like to target preventive measures toward.

I certainly appreciate the opportunity to deliver this testimony, and I would be very pleased to answer any questions you may have.

[Prepared statement of Dr. Bennett appears in the appendix.]

Senator BURDICK. Thank you.

Dr. RHOADES. Mr. Burdick, Mr. Leonard does not have a prepared statement, but appears at the invitation of the committee to answer questions, and is prepared to do so.

Senator BURDICK. Dr. Rhoades, I have before me excerpts of the report of the Secretary's Task Force on Black and Minority Health. It was issued January of this year. The report of the subcommittee on diabetes, of which you were a member, states the following:

> The increased diabetes in Native Americans can only be termed as epidemic. Extensive innovative efforts are needed to interrupt the increasing prevalence of diabetes among the North Native Americans and reduce morbidity and mortality.

Dr. Rhoades, when this report was issued, did you dissent from these particular findings and recommendations?

Dr. RHOADES. No, sir.

Senator BURDICK. Then I assume that you support them?

Dr. RHOADES. I agree that those are true statements.

Senator BURDICK. Does the administration differ from the conlcusions of the task force?

Dr. RHOADES. I am not prepared to speak for the administration as it relates to the Secretary's Report on Black and Minority Health, Mr. Chairman.

Senator BURDICK. As Director of the Indian Health Service, how do you reconcile the task force findings with the administration's position on the legislation which is currently being considered by this committee?

Dr. RHOADES. I think the explanation for that comes readily to my mind. That is, notwithstanding the factuality of the observations and recommendations made in the Secretary's task force report, it does not necessarily follow that specific legislation is required to provide that correction. We believe that the authorities that exist at the present time are sufficient to address those specific problems that are raised by the task force report.

Senator BURDICK. Reading again what I just read, that, "Extensive innovative efforts are needed," can we put forth extensive innovative efforts with the present budget?

Dr. RHOADES. Yes; I believe that we can, and have, put forth extensive innovative efforts, although I readily admit that what might be described as innovative may not be by another. In fact, I believe that many of the activities carried out by Dr. Gohdes since 1979 were and are innovative and they were and are extensive.

Senator BURDICK. I have listened to these witnesses the last 1½–2 hours, and all I hear are high percentages—50 percent, the Pima 15 times somebody else, the Pima Reservation. I hear about these high numbers. Certainly, this requires something more than just a

passing review. This requires some action, I would think. How long can we let these percentages continue at that rate? Certainly, innovative efforts, that means some few extra dollars and a few extra people. Do you disagree with that? Do you think you've got the people and you've got the dollars?

Dr. RHOADES. No, no; I think that describes exactly the situation. It describes the dilemma that we have in the Indian Health Service in the allocation of those resources. It's clear that we've heard today that diabetes is a manor porblem.

I attend approximately a meeting a week where, depending upon the group present, I address the major problem. This has included, in the last several months: child health; pregnant women; destructive behavior of young males; alcoholism; depression and other mental problems of Indians; problems of the elderly. I think the recitation of the urgent problems goes on and on.

The question is how to prioritize among the problems competing for allocation of those resources. It is a valid question, and I don't propose that we are wise enough to answer it in the best possible way. Nevertheless, within the resources that are available, $1.9 million is now specifically used to address that problem. But by no means does it represent more than a small proportion of all of the efforts that exist in the Indian Health Service today addressed to diabetes.

Senator BURDICK. I suppose it goes without saying that $5 million would do a better job than $1.9 million. The bill calls for that next year, $5 million. But CBO has——

Dr. RHOADES. I am sorry; I didn't hear the question.

Senator BURDICK. I say, with the CBO estimate of $5 million, you could do more than you can with your $1.9 million.

Dr. RHOADES. Yes; of course.

Senator BURDICK. Is the Indian Health Service aware of the numerous complaints in the tribal CHR and tribal health directors about weaknesses in the IHS service delivery, but specifically that the Mescalero and Apache Tribes have not had a health educator for the past 15 years, that the IHS hospitals serving the United Itowah-Cherokee Tribes in Oklahoma do not have a diabetes education or drug or alcohol abuse program, that there is little direct communication between tribal health care providers at the Indian Health Service and outreach preventive efforts for diabetes? Do you acknowledge those facts to be correct?

Dr. RHOADES. I can't speak for some of those specific examples, which I must say have not come to my attention. I would reserve some degree of skepticism if a careful examination were to disclose that that is absolutely accurate. Otherwise, I have no reason to dispute them.

For example, the community health representative program is a program that is contracted entirely to tribes, and tribes have great, great latitude in how those CHR's choose to deliver care. And I dare say it's well within the purview of the Mescalero Tribe to establish that within their CHR programs if they so chose.

Senator BURDICK. I understand that this year the administration recommended no funding whatever for CHR's this year.

Dr. RHOADES. That is correct.

Senator BURDICK. There isn't much they can do if the money isn't there.

Dr. RHOADES. No.

Senator BURDICK. There will be several questions submitted to you, Doctor. If you would answer them for the record, we would appreciate it. It would save some time.

Dr. RHOADES. We would be happy to.

Senator BURDICK. Thank you very much.

Dr. RHOADES. Thank you, sir.

Senator BURDICK. The meeting will be in recess till the sound of the gavel.

[Recess.]

Senator GORTON [presiding]. Dr. Horton, you may proceed.

STATEMENT OF EDWARD S. HORTON, M.D., MEMBER, NATIONAL DIABETES ADVISORY BOARD, BURLINGTON, VT, ACCOMPANIED BY NEAL FRIEDMAN, PRESIDENT, AMERICAN DIABETES ASSOCIATION, NEW MEXICO AFFILIATE

Dr. HORTON. Mr. Gorton, I am Dr. Edward Horton, from the University of Vermont College of Medicine. I am professor and associate chairman of the department of medicine and director of the division of endocrinology and metabolism there. I am also a member of the National Diabetes Board. And I appreciate the opportunity to appear here today before you to present the recommendations, and support, of the National Diabetes Advisory Board for S. 1988.

The National Diabetes Advisory Board was established by Congress 10 years ago to review, evaluate, and report on national diabetes-related activities. Since the beginning, the board has described and reported on the extent of diabetes and its complications among American Indians and made recommendations to combat this rapidly growing problem.

The board now strongly supports S. 1988, and if enacted, we feel that this bill will be a very postitive step forward toward combatting the problem of diabetes in native Americans.

We've heard a lot of testimony this morning regarding the problem of diabetes. I would like to summarize my own testimony by making a few brief comments on the magnitude and importance of diabetes in native Americans and on the specific provisions of this bill.

Whether expressed in terms of prevalence, morbidity, premature mortality, or merely economic impact, diabetes among American Indians is significantly more severe than in other U.S. population groups. We have heard that the incidence of diabetes varies from one Indian tribe to another. In the Pima Indians in Arizona it is as much as 50 percent or even more than 50 percent of the adult population has diabetes. In other Indian tribes the estimates are somewhere around 20 percent of the adult population with diabetes.

This is truly an epidemic. There is no question that when 50 percent of an adult population is stricken with a disease which is a chronic disease and has long-term complications which lead to such conditions as blindness, kidney failure, diseases of the nerves, amputations and so forth, that we are dealing with major health problem in this population of people.

Some indication of the seriousness of diabetes, merely from the point of view of the economic impact, is that as the incidence of diabetes has been increasing over the last 20 years, we are now beginning to see the full impact of long-term complications of the disease which often do not appear for 10 to 15 years after the onset of the diseases. There is a marked increase in the number of patients who have developed end-stage renal disease, requiring kidney dialysis and transplanation. It's estimated that at the present time this is costing approximately $10 million per year and these costs are rapidly increasing.

American Indians with diabetes account for approximately 75 percent of all amputations that are done within the Indian Health Service health care system, and the hospital-related costs alone of this are over $3 million, to say nothing of the additional costs involved with this. And I could go on with other conditions, like blindness and so forth.

Now, cost-effective prevention and treatment strategies are available to reduce both the rate and——

Senate GORTON. Doctor, if you'll let me interrupt——

Dr. HORTON. Yes, sir.

Senator GORTON. As other members have, I am very pressed and have to leave before 12:30. I would appreciate your summarizing your statement. The written statement will be included with your statement. The written statement will be included in the record. That way we can hear Dr. Friedman.

Dr. HORTON Yes, sir; I would be happy to.

I would like then to turn to comments on the specific provisions of this bill and why we believe that they are needed. I would like to start by saying that the present programs of the model diabetes care centers that the Indian Health Service has formed are an excellent program, but they are simply not enough.

Section 3 of the bill, which calls for a study of diabetes among native Americans, is clearly needed because of the rapid increase and changing situation that we're dealing with. We simply do not have the data regarding incidence and prevalence and the rate of development of long-term complications of the disease. We need more information.

Section 4 of the bill, which calls for a diabetes care program expansion, has really targeted three major areas: one, the prevention of diabetes by education and preventive measures; second, the early recognition and treatment of the disease before complications develop; and finally, the treatment of complications once they have existed.

We do know a great deal about all of these areas now, and there are effective strategies that could be used. The problem is simply getting it out there where it's needed.

The bill calls for a training program at all levels. This is very important. It's estimated that the physicians and other health care providers in the Indian Health Service are turned over every 5 years. In other words, there are 20 percent of people entering Indian Health Service that are new each year, and so there is a tremendous need to train the new people coming in.

There is also a tremendous need to train people who are working at the community level. So we strongly support this.

The bill calls for the creation of new model diabetes programs. I think this is very important. There are currently seven in existence. They're excellent programs, but they're only reaching about 10 percent of the diabetics. So we need a marked expansion in that area.

Finally, we need marked expansion of outreach programs to get the community educational services, local programs going in education, and prevention and treatment of the disease.

Finally, diabetes control officers are called for. They are very important in each of the regions to have an officer who can coordinate all of these activities.

Section 5 calls for data collection and analysis. This is to track the problem. We do need a comprehensive data system to continue to monitor the prevalence and incidence of the disease and its complications in various geographic areas. We need information about the medical services that are required to handle the problem of diabetes. So this is also important.

Finally, section 6 calls for increased support for research in this area. We strongly support this. We need to have increased attention to the causes, diagnosis, and treatment and prevention of the disease. Currently, the National Institutes of Health, and specifically the National Institute of Diabetes, Digestive, and Kidney Disease, is a major funding agency in this area. And Dr. Bennett has already described some of the activities going on in this area, but we certainly need more.

My final comment is that recently the National Diabetes Advisory Board, in collaboration with the National Congress of American Indians and the National Indian Health Board, has completed a survey of 153 Indian tribes regarding their awareness of the problem of diabetes in the population and what their desires are to receive some assistance in this area; 100 percent of the tribes are aware of the problem of diabetes in native Americans; 91 percent want some form of help; 22 percent have developed some program on their own; 54 percent are aware of the model diabetes programs, but only 33 percent have actually benefited or interacted in some way with this program.

The bottom line is that we need to do more in this area. The current budget of $1.9 million has been recommended by the National Diabetes Board to be increased to $2.9 million in fiscal year 1987, but even that is not enough to really solve the problem. Thank you.

[Prepared statement of Dr. Horton appears in the appendix.]

Senator GORTON. Thank you.

Dr. Friedman.

Dr. FRIEDMAN. Yes; Senator Gorton, Senator Melcher. I would like to present a corrected copy for the record. I would like to present a brief summary of my statement to the committee.

Senator GORTON. We will substitute the corrected copy, as if read in full, and we'd be happy to have you summarize.

Dr. FRIEDMAN. Thank you. My name is Dr. Neal Friedman. I am currently president of the New Mexico affiliate of the American Diabetes Association and the chairman of the Department of Endocrinology at Lovelace Medical Center in Albuquerque, NM. I am also an associate clinical professor at the University of New Mexico.

Between 1976 and 1978 I was with the Indian Health Service at Zuni Pueblo in New Mexico, where I participated in the development of the first diabetes clinic.

The American Diabetes Association is a nonprofit organization that has over 800 affiliates and chapters nationwide and more than 220,000 members, including laypersons, physicians, research scientists, nurses, dieticians, and educators. The purpose of the ADA is to promote research relating to curing and preventing diabetes and to improve the well-being of people with diabetes, and their families. The American Diabetes Association is pleased to be able to participate in this hearing on the Native American Diabetes Prevention and Control Act of 1985, S. 1988.

We have consistently supported existing programs that seek to address the problem of diabetes within the native American population, with particular emphasis on the Model Diabetes Care Program operated by the Indian Health Service out of Albuquerque, NM.

Unfortunately, current efforts are clearly inadequate to meet the growing incidence of and health impact of diabetes among American Indians. For this reason, we wholeheartedly recommend the enactment of S. 1988.

The prevalence and impact of diabetes among native Americans is significantly greater than among other population groups. I would like to quote some recent figures from the 7,000-member Zuni Pueblo and some other tribes concerning the effect of diabetes and the treatment of kidney failure. The present incidence of diabetes above the age of 35 in Zuni is 25 percent. In 1978, when I was in Zuni, the incidence of diabetes was 25 percent above the age of 45; 50 percent of the Zuni population, however, is less than 16 years old. Thus, there is a huge population at future risk.

The incidence of kidney failure among the entire U.S. population is 354 per million. The incidence in Zuni is 3,170 per million—33 percent from diabetes mellitus. The incidence in the Pima population is 2,170 per million—90 percent from diabetes mellitus. The present cost per patient is $25,000 per year for dialysis. The cost to Zuni Pueblo per year for treatment of end-stage renal disease from diabetes mellitus is $.5 million, and increasing each year.

The American Diabetes Association is in full agreement with the conclusion of the Secretary's Task Force on Black and Minority Health that stated, "Extensive innovative efforts are needed to interrupt the increasing prevalence of diabetes among North American Indians and reduce morbidity and mortality." And that is a quotation.

Having agreed that his compelling need exists, we are pleased to offer our comments on S. 1988. Mr. Chairman, we have a number of observations to offer with regard to the specific provisions of the bill. These comments are set forth in detail in our written testimony. At this time, I will summarize a few of the most important points.

First, we wholeheartedly endorse the legislation's directive that the Secretary continue to maintain existing model diabetes clinics and that the number of model clinics be expanded. The model clinics have achieved considerable progress in delivering diabetes care within a limited number of diabetes tribes.

Another important area for emphasis is the need to screen all individuals who go through the Indian health care system for diabetes in order to reduce incidence and forestall future complications. We recommend that the legislation be clarified to provide for a uniform diabetes screening process to be implemented at all IHS facilities.

The ADA also wishes to emphasize the need to ensure that all IHS health care personnel are fully trained in the appropriate techniques for diagnosing and treating patients with non-insulin-dependent diabetes.

We strongly endorse section 4(a)(3) of the bill requiring training programs, and we recommend that these efforts focus on non-insulin-dependent diabetes. The ADA hopes to cooperate in a public and private sector effort to develop such programs.

Finally, we endorse the bill's directive that diabetes educational programs be expanded and that funds be provided to hire qualified personnel. It is essential that the model clinics receive the support necessary for dissemination of resources and information from clinics out into the field. We recommend that at least one full-time diabetes control officer be hired and assigned to each IHS administrative unit.

Type II diabetes mellitus is a difficult disease to treat. It is a behavioral disorder occurring in a population that has profound genetic predisposition. It is also a new disease in this population that was rarely described before 1940. Thus, the present Indian population is only recently becoming aware of its devastating effects.

The causes of diabetes are changes in diet from legumes and grains to fat, sugar, and high-calorie processed foods, and a marked decrease in exercise as the population has changed from farming, ranching, and hunting to less labor-intensive jobs and lifestyles. The accompanying increase in obesity has further increased the incidence of diabetes and caused it to occur at a younger age.

Thus, the most effective treatment of type II diabetes is not a physician in an office, at the hospital or clinic, prescribing insulin or oral hypoglycemic agents. The most effective treatment in the Indian and non-Indian population has involved behavior modification of patients or groups of patients by community-based health educators under the direction of a phyician.

This team approach has stressed modification of diet, exercise, and lifestyle to attain a cure. This is the approach being pioneered in the native American population by the Model Diabetes Care Program and the Zuni Fitness and Weight-Control Program.

In conclusion, the American Diabetes Association urges the committee to support these increased efforts to curb the effects of diabetes among native Americans. We endorse S. 1988 unequivocally and will gladly assist the Secretary to carry out these important new initiatives.

Thank you for this opportunity to testify. We would be more than happy to respond to any questions that the committee may have.

[Prepared statement of Dr. Friedman appears in the appendix.]

Senator GORTON. Dr. Friedman, thank you very much.

If we have any questions, or if any of the members do, we will submit them to you in writing. We appreciate the forceful and elo-

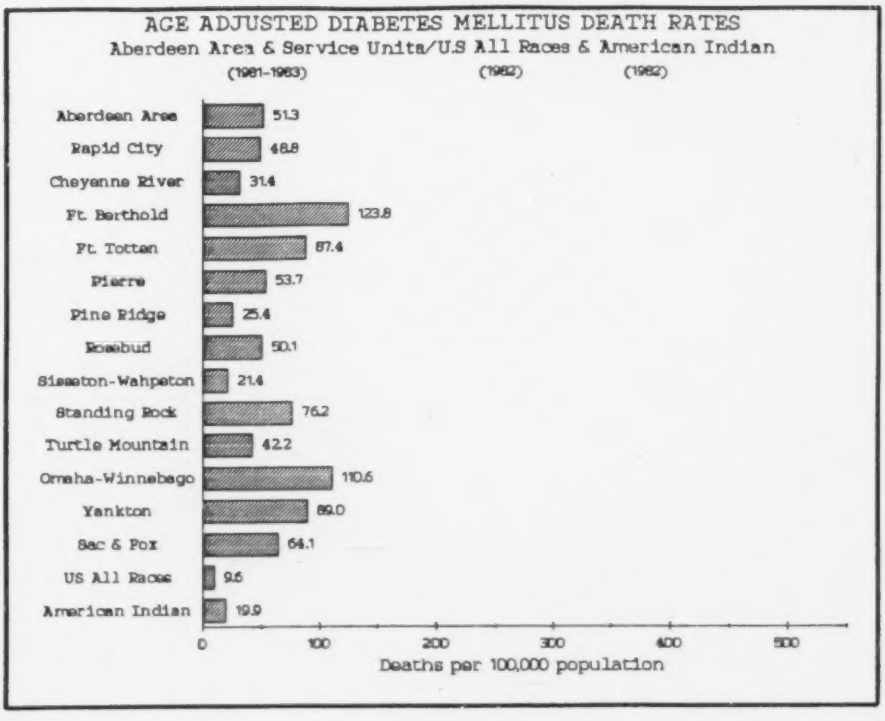
quent testimony of both you as witnesses, and of course the earlier witnesses.

With that, the meeting is adjourned.

[Whereupon, at 12:32 p.m., the committee was adjourned.]

APPENDIX

Additional Material Submitted for the Record



PREPARED

STATEMENT OF SENATOR JOHN MELCHER

GOOD MORNING LADIES AND GENTLEMEN. THE PURPOSE OF THE HEARING TODAY IS TO RECEIVE TESTIMONY ON S. 1988, THE NATIVE AMERICAN DIABETES PREVENTION AND CONTROL ACT OF 1985. I WELCOME EACH OF YOU AND AM PLEASED TO NOTE THAT MR. JOHN BUFFALOHORN, PRESIDENT OF THE NORTHERN CHEYENNE TRIBE AND MR. CALEB SHIELDS, COUNCIL MEMBER FROM THE ASSINIBOINE AND SIOUX TRIBES, ARE PRESENT TO TESTIFY ON S. 1988.

THIS PIECE OF LEGISLATION IS DESIGNED TO ADDRESS ONE OF THE MOST SERIOUS AND FAR REACHING HEALTH PROBLEMS AFFECTING NATIVE AMERICANS. THE INCIDENCE OF DIABETES AMONG NATIVE AMERICANS IS DEPLORABLE -- IN MANY TRIBES, THE INCIDENCE EXCEEDS 40% AS COMPARED WITH 3% IN THE GENERAL U.S. POPULATION.

THE CONSEQUENCES OF DIABETES AMONG NATIVE AMERICANS ARE SERIOUS AND LONG TERM. FAILURE TO PREVENT AND CONTROL THE DISEASE RESULTS IN KIDNEY FAILURE, AMPUTATION, BLINDNESS AND EARLY DEATH. THE TRADEGY OF DIABETES FOR NATIVE AMERICANS IS THAT ONE OUT OF FIVE ADULTS ARE AFFECTED; THE HOPE IS THAT THE DISEASE CAN BE PREVENTED AND CONTROLLED.

S. 1988 WILL REQUIRE THE INDIAN HEALTH SERVICE TO EXPAND AND IMPROVE ITS WORK IN THE PREVENTION AND CONTROL OF DIABETES. I AM PLEASED TO NOTE THAT THE IHS HAS AN EXISTING DIABETES PREVENTION AND CONTROL EFFORT WHICH HAS SHOWN GOOD RESULTS ON A LIMITED BASIS.

THIS LEGISLATION WILL BUILD ON THE EXISTING EFFORT TO ENSURE THAT THE DISEASE IS PREVENTED AND COMBATED AT EVERY LOCAL LEVEL. IT REQUIRES RESEARCH; THE DEVELOPMENT AND IMPLEMENTATION OF COMPREHENSIVE PROGRAMS FOR PREVENTION AND CONTROL; THE ESTABLISHMENT OF NEW MODEL DIABETES TREATMENT CENTERS; TRAINING FOR HEALTH CARE PROVIDERS, INCLUDING CHRs; AND DATA COLLECTION TO SUPPORT THE DISSEMINATION OF INFORMATION ABOUT PREVENTION AND CONTROL. IN SHORT, S. 1988 RECOGNIZES THAT WHILE THE IHS HAS MADE A START TO PREVENT AND CONTROL DIABETES, MUCH MORE NEEDS TO BE DONE TO ERADICATE AND CONTROL THIS DISEASE WHICH IS WRECKING HAVOC WITH THE LIVES AND FUTURE OF NATIVE AMERICANS.

I AM PLEASED TO SPONSOR THIS BILL WHICH IS CRITICALLY NEEDED TO ENSURE THAT DIABETES IS SYSTEMATICALLY AND COMPREHENSIVELY ADDRESSED.

MARK ANDREWS, NORTH DAKOTA, CHAIRMAN
BARRY GOLDWATER, ARIZONA
BLADE GORTON, WASHINGTON
FRANK H. MURKOWSKI, ALASKA
JAMES ABDNOR, SOUTH DAKOTA
JOHN MELCHER, MONTANA
DANIEL K. INOUYE, HAWAII
DENNIS DeCONCINI, ARIZONA
QUENTIN N. BURDICK, NORTH DAKOTA
PETER B. TAYLOR, STAFF DIRECTOR
PAUL I. NICHTMAN, MINORITY STAFF DIRECTOR

United States Senate
SELECT COMMITTEE ON INDIAN AFFAIRS
WASHINGTON, DC 20510

MEMORANDUM

April 14, 1986

TO: Senator John Melcher, Ranking Minority Member and Members of the Select Committee on Indian Affairs

FROM: Luis De Ortube, M.D., Professional Staff Member

RE: Hearing on S. 1988, a bill to establish a program for the prevention and control of diabetes among Native Americans.

BACKGROUND

S. 1988 will require the Indian Health Service to improve and expand its activities to prevent and control diabetes among the Native American population. The goal is to reduce the incidence of the disease to a rate comparable with the general United States population.

The bill is based on investigative work conducted by the Select Committee on Indian Affairs. Site visits to the Navajo and Pima Reservations documented the field conditions for prevention and control of diabetes. Further, a comprehensive telephone survey was conducted to determine the extent of the disease and the capabilities for treatment and prevention on each reservation. Numerous complaints were gathered including: a lack of or inadequate medical facilities for treatment; patient overcrowding in existing facilities; the dispensing of expired drugs; a lack of diabetes education; a high prevelance of diabetes, hypertention, mental health problems and drug and alcohol abuse.

There are 51 Indian Health Service hospitals and several hundred clinics serving approximately 1,000,000 Native Americans. Seven model diabetes clinics exist in Oklahoma, North Dakota, Arizona, Nebraska, New Mexico, Maine and Washington but these only service 10% of the Native American population. Statistics indicate that as much as 40% of the Native American population is afflicted by the disease. Statistics show a continuous rise of diabetes in the Native American population. The mortality rate for Indians from diabetes is 19% at an average age of 45 - 65 years, compared with a 9% average for other ethnic groups. 76% of the lower extremity amputations and 78% of dialysis patients among Native Americans are attributed to diabetes.

Epidemiologists and researchers are still working to ascertain the primary cause of diabetes mellitus. There is strong evidence, however, to substantiate that the prevelance of the disease is much higher in the Native American population than in other ethnic groups. A high fat diet and lack of exercise are thought to be contributing factors; in addition, some obese Native American diabetics have developed "insulin resistance" which poses a great challenge for treatment.

SECTION-BY-SECTION ANALYSIS OF S. 1998, A BILL TO ESTABLISH A PROGRAM FOR THE PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS TO BE CITED AS THE "NATIVE AMERICAN DIABETES PREVENTION AND CONTROL ACT OF 1985".

Section 2: Section 2 expresses the findings of the Congress with regard to the incidence of diabetes in the Native American population as compared to its incidence in the general population; the increasing frequency of complications of diabetes in the Native American population; and the projection that the health care costs related to the treatment of diabetes and its complications can be expected to increase significantly over the long term unless the Department of Health and Human Services determines the cause of diabetes among Native Americans and develops early diagnosis, treatment, and prevention programs to reduce the incidence of diabetes among Native Americans; and trains and provides for the training of health care providers in the diagnosis, treatment and control of diabetes and related complications. Section 2 further expresses the findings of the Congress as the existence of a Model Diabetes Control program within the Indian Health Service and the need to implement outreach services and to convey treatment strategies from model project sites. Section 2 also outlines the purposes of the Act as broadening the Department's research program relating to diabetes and related complications among Native Americans; strengthening the diabetes treatment efforts of the Indian Health Service by implementing a diabetes and related complications prevention and control program on each Indian reservation, Alaska Native village, and in the State of Hawaii; achieving a reduction in the incidence of diabetes among Native Americans to a rate that is comparable to that of the general United States population.

Section 3: Section 3 directs the Secretary of Health and Human Services to determine the incidence of diabetes among Native Americans and the activities that should be undertaken by the Indian Health Service to reduce the incidence of diabetes in the Native American population; provide guidance in the prevention, treatment, and control of diabetes to Native Americans; to provide early diagnoses of diabetes in

proper continuing health care is provided to diabetic Native Americans. The Secretary is also directed to determine the fiscal impact to the Federal government of treating the long-term complications of diabetes based upon the existing prevalence and incidence of diabetes among Native Americans. Section 3 further directs the Secretary to prepare an inventory of all public and private health care programs and resources within the United States that are available for the treatment, prevention, or control of diabetes among Native Americans. Section 3 directs the Secretary to submit a report to the President and the Congress within eighteen months of enactment, describing the determinations made pursuant to the directives of the Act and describing authorized research activities.

Section 4: Section 4 directs the Secretary of Health and Human Services to implement a program designed to strengthen and expand the diabetes control program of the Indian Health Service and which will enable all Indian Health Service service units to effectively treat newly diagnosed diabetics, individuals with a high risk of becoming diabetic, and the short- and long-term complications of diabetes. The Secretary is also directed to conduct training programs relating to current methods of prevention, diagnosis, and treatment of diabetes and related complications among Native Americans for federal, tribal, and other Native American health care providers including community health representatives. The Secretary is further directed to determine the appropriate delivery of health care services relating to diabetes; to develop and present health education information to Native American communities and schools concerning the prevention, treatment, and control of diabetes; and to ensure that proper continuing health care is provided to Native Americans who are diagnosed as diabetic. Section 4 directs the Secretary to promote coordination and cooperation in the delivery of diabetes related services among all health care providers and to encourage and fund joint projects between Federal and tribal health care facilities and Native American communities for the prevention and treatment of diabetes. Section 4 further directs the Secretary to continue to maintain existing model diabetes clinics at the Claremore Indian Hospital in Oklahoma; the Fort Totten Health Center in North Dakota; the Sacaton Indian Hospital in Arizona; the Winnebago Indian Hospital in Nebraska; the Albuquerque Indian Hospital in New Mexico; the Terry, Princeton, and Old Town Health Centers in Maine; and the Bellingham Health Center in Washington. The Secretary is directed to establish and maintain additional model diabetes clinics in Minnesota, Montana, Hawaii, and on the Navajo and Papago Indian reservations. The Secretary is further directed to develop and implement an outreach program to ensure that the

achievements and benefits derived from the activities of the model diabetes clinics are used by all Indian Health Service service units in the diagnosis, prevention, and treatment of diabetes among Native Americans. Section 4 directs the Secretary to maintain appropriate personnel within the Indian Health Service to develop and implement the provisions of the legislation and to manage and coordinate the Indian Health Service's diabetes care program. Section 4 also directs the Secretary to submit an annual report to the Congress outlining the activities, achievements, needs, and future goals of the Indian Health Service's diabetes care program.

Section 5: Section 5 directs the Secretary to develop and maintain a comprehensive standardized system within the Indian Health Service for the collection, analysis, and reporting of data relating to diabetes and associated complications among Native Americans. The mandated system is to be designed to facilitate dissemination of the best available information on diabetes to Native American communities and health care professionals. Section 5 requires that the system be operational within two years after the date of enactment of the legislation.

Section 6: Section 6 directs the Secretary to require of each agency and unit of the Department of Health and Human Services that conducts research relating to diabetes, that such agency or unit give special attention to research concerning the causes, diagnosis, treatment, and prevention of diabetes and related complications among Native Americans; and that each agency or unit coordinate such research with all other agencies and units of the Department that conduct research relating to diabetes and associated complications.

Section 7: Section 7 authorizes the Secretary to prescribe such regulations as may be necessary to carry out the provisions of the legislation.

Section 8: Section 8 authorizes such sums as may be necessary to carry out the provisions of the legislation.

LEGISLATIVE HISTORY

S. 1988 was introduced on December 19, 1985 by Senators Melcher, Inouye, DeConcini, Burdick, Abdnor and Bingaman. It was referred to the Select Committee on Indian Affairs and a hearing was scheduled for April 15, 1986.

On February 27, 1986, Representative Pat Williams introduced a companion bill, H.R. 4282, in the House of Representatives. Currently there are 20 cosponsors. The bill has been referred to two House committees, Interior and Insular Affairs and Energy and Commerce, but no hearings have been scheduled.

A copy of the bill was mailed to each of the Tribal Chairmen asking for their review and comment. Approximately 20 tribes responded either by letter or telephone to express strong support.

The Administration is opposed to the bill on the basis that it is not needed to continue or improve the IHS diabetes program. They assert that the bill could narrow the focus of other health efforts by drawing limited funds from other priority projects.

CONGRESSIONAL BUDGET OFFICE
U.S. CONGRESS
WASHINGTON, D.C. 20515

Rudolph G. Penner
Director

April 14, 1986

Honorable John Melcher
United States Senate
Washington, D.C. 20510

Dear Senator:

In response to your request on January 23, 1986, the Congressional Budget Office has prepared the attached preliminary cost estimate for S. 1988, the Native American Diabetes Prevention and Control Act of 1985, as introduced on December 19, 1986.

If you wish further details on this estimate, we will be pleased to provide them.

With best wishes,

Sincerely,

Rudolph G. Penner

cc: Honorable Mark Andrews
Chairman
Select Committee on Indian Affairs

CONGRESSIONAL BUDGET OFFICE
COST ESTIMATE

April 14, 1986

1. BILL NUMBER: S. 1988

2. BILL TITLE:

Native American Diabetes Prevention and Control Act of 1985.

3. BILL STATUS:

As introduced by Senator Melcher on December 19, 1985 and referred to the Senate Select Committee on Indian Affairs.

4. BILL PURPOSE:

To establish a program for the prevention and control of diabetes among Native Americans.

5. ESTIMATED COST TO THE FEDERAL GOVERNMENT:

(by fiscal years, in millions of dollars)

	1987	1988	1989	1990	1991
Estimated Authorization Level					
Study	0.2	0.1	--	--	--
Diabetes Care Program					
Training	2.0	2.1	2.1	2.2	2.3
Model Clinics	1.0	1.0	1.1	1.1	1.2
Additional IHS Personnel	0.8	0.8	0.9	0.9	0.9
Educational Materials	0.5	--	--	--	--
Subtotal	4.3	3.9	4.1	4.2	4.4
Data Collection	2.0	2.1	2.1	2.2	2.3
Research Coordination	0.1	0.1	0.1	0.1	0.1
Total Estimated Authorization Level	6.6	6.2	6.3	6.5	6.8
Estimated Outlays					
Study	0.2	0.1	--	--	--
Diabetes Care Program	3.2	3.8	4.1	4.1	4.4
Data Collection	1.5	2.0	2.1	2.1	2.2
Research Coordination	0.1	0.1	0.1	0.1	0.1
Total Estimated Outlays	5.0	6.0	6.3	6.3	6.7

The costs of this bill fall within function 550.

Basis of Estimate

The bill authorizes such sums as may be necessary to carry out the activities described. CBO assumes all authorized amounts are fully appropriated at the beginning of each fiscal year. Outlays are estimated using spendout rates computed by CBO on the basis of recent program data. Authorization levels are subject to subsequent appropriations action.

S. 1988 has four parts that would result in costs to the federal government. The bill authorizes the Secretary of Health and Human Services to conduct an 18 month study on the incidence of diabetes among Native Americans and how to reduce it. The study would include the fiscal impact on the federal government of treating the long-term effects of diabetes and include an inventory of all health care resources available to treat and prevent diabetes among Native Americans. Costs of the study are expected to be about $300,000 for the 18 months.

The bill also authorizes the Secretary to implement a diabetes care program. As part of this program, training would be provided for health care providers and community health representatives on prevention, diagnosis, and treatment of diabetes. CBO estimates the cost of this training to be about $2 million in each year. Costs include wages and travel for trainers and per diem and travel for trainees. This estimate assumes 80 hours of training would be provided to all community health representatives and to one person from each Indian health care facility.

The diabetes care program would also include establishing five new model diabetes clinics in areas specified in the bill. The Indian Health Service currently supports seven such model clinics at a cost to the Service of about $200,000 for each clinic each year. The majority of this covers salaries for the health care professionals and others operating the clinic. If the five new clinics provide the same level of services as the current clinics, additional costs to the federal government could be about $1 million each year.

The bill authorizes maintenance of the necessary Indian Health Service (IHS) personnel to implement the Act and to administer the diabetes care program. CBO estimates that at least an additional 40 full-time equivalents (FTE's) would be needed to implement and administer the diabetes care program. The five new model diabetes clinics would require an additional 25 FTE's. The model clinics currently operating have an average of 5 FTE's employed at each site. Costs for these 25 additional FTE's have been included in the above estimate for the model diabetes clinics. The remaining 15 FTE's could be required to administer the diabetes care program. The

alcoholism program currently operated by IHS is managed by 5 FTE's at the agency office and about 10 FTE's in the service areas. If a similar level of program administration is used for the diabetes care program, an additional 15 FTE's would be needed at a cost of about $800,000 each year.

The Secretary is also authorized to develop health education information concerning diabetes for Native American communities and schools. If $1,000 were spent for the development and provision of diabetes educational materials at each Bureau of Indian Affairs contract school and at public schools with significant Native American populations the cost would be about $500,000.

There are several aspects of the diabetes care program mentioned in the bill for which CBO has shown no costs in this estimate. For example, the bill mentions that the diabetes care program shall be designed to enable all service units of the IHS to effectively treat diabetes and to ensure that proper continuing health care is provided. The bill also states that the Secretary shall fund joint projects concerning diabetes involving federal and tribal health care facilities and Native American communities. CBO has no basis to estimate the cost of several such activities mentioned in the bill or the level of federal involvement that might be undertaken by the Secretary to comply with the bill language.

The bill also authorizes the Secretary to develop a data collection and analysis system relating to diabetes. The federal government currently operates a similar system that collects and analyzes data on smoking at a cost of about $2 million each year. Similar costs could be expected to result from the diabetes data collection system.

Finally, the bill authorizes the Secretary to require each agency within HHS conducting research on diabetes to give special attention to research concerning Native Americans and to coordinate that research within HHS. CBO cannot anticipate how the Secretary might require agencies to "give special attention" to this type of research or the resulting costs. Coordinating diabetes research relating to Native Americans could be accomplished by hiring a coordinator to monitor the department's efforts at a cost of less than $100,000 each year.

6. ESTIMATED COST TO STATE AND LOCAL GOVERNMENT:

The budgets of state and local governments would not be affected directly by the enactment of this bill.

7. ESTIMATE COMPARISON: None.

8. PREVIOUS CBO ESTIMATE: None.

9. ESTIMATE PREPARED BY: Carmela Dyer (226-2820)

10. ESTIMATE APPROVED BY:

for James L. Blum
Assistant Director
for Budget Analysis

62-673 O - 86 - 3

STATE OF HAWAII
OFFICE OF HAWAIIAN AFFAIRS
567 SOUTH KING STREET, SUITE 100
HONOLULU, HAWAII 96813
(808) 548-9860

PREPARED STATEMENT OF KAMAKI KANAHELE III

Good morning Mr. Chairman and members of the Committee. My name is Kamaki Kanahele III, and I am the Administrator of the Office of Hawaiian Affairs. I would like to thank Senator Mark Andrews, Chairman of this Committee, for scheduling this important hearing. The Office of Hawaiian Affairs strongly supports adoption of Senate Bill 1988.

Before continuing, however, I would like to share with you a little background on the Office of Hawaiian Affairs as a means of providing the members of the Committee with some understanding of the role and interest of OHA in this matter.

THE OFFICE OF HAWAIIAN AFFAIRS

The Office of Hawaiian Affairs is governed by an elected nine-member Board of Trustees. The trustees must be of native Hawaiian descent and are elected by eligible voters who must also be of native Hawaiian ancestry. As a result, the OHA trustees are directly accountable to their beneficiaries, the native Hawaiian people.

OHA was created in 1978 by an amendment to the Hawaii State Constitution. The basis for its establishment, however, dates back to our State Admission Act of 1959. The Act created a public land trust, the proceeds of which were to be used for five purposes. One of the purposes was the betterment of conditions for native Hawaiians.

In 1979 the State Legislature passed Act 196 which established the basic structure of OHA. This act, which was subsequently codified as Chapter 10, Hawaii Revised Statutes, set out the basic purposes, powers, duties and responsibilities of OHA. For your convenience, a copy of Chapter 10 is attached as Appendix A. Chapter 10 established OHA as the "principal public agency in this State responsible for the performance, development, and coordination of programs and activities relating to native Hawaiians." Chapter 10 also mandates OHA to serve as a receptacle for reparations and to act as a clearinghouse for federal or state assistance involving Hawaiian programs and projects. OHA is also responsible for advising, informing and coordinating federal, state and county activities relating to native Hawaiian programs. It is with this role in mind that OHA submits this testimony today.

SENATE BILL 1988

Provisions of Senate Bill 1988 that affect native Hawaiians are those that charge the Secretary of Health and Human Services to conduct a study to determine the incidence of diabetes among native Americans, including native Hawaiians; the activities that will reduce the incidence of diabetes; guidelines in the prevention, treatment and control of diabetes; activities to provide early diagnosis and to ensure proper continuing health care for diabetic native Americans. The mandated study also includes an examination of the fiscal impact to the federal government on long-term complications of diabetes and an inventory of all health care programs and resources for the prevention, treatment and control of diabetes among native Americans.

Senate Bill 1988 further directs the Secretary of Health and Human Services to implement a diabetes care program which will provide training for health care providers; determination of appropriate delivery of diabetes health care services to native Americans; the development and presentation of relevant health care information; proper health care to diabetic native Americans and model diabetes clinics, including one in Hawaii.

Senate Bill 1988 also requires the Secretary to conduct and coordinate research, data collection and analysis within the Department regarding diabetes among native Americans.

THE NEED FOR SENATE BILL 1988 IN THE NATIVE HAWAIIAN COMMUNITY

Senate Bill 1988, and its provisions ennumerated above, are especially important to native Hawaiians who suffer from diabetes more frequently than other ethnic groups in the State. According to a recent study funded by the U. S. Department of Health and Human Services, E Ola Mau, the Native Hawaiian Health Needs Study, and in which OHA participated, native Hawaiians have been found to have the highest prevalence of diabetes of any other ethnic group in the State. (The chapter on diabetes from E Ola Mau is attached as Appendix B.) In addition, many factors associated with diabetes are characteristic in the Hawaiian population. For example, E Ola Mau found that "increased frequency of diabetes appears to be associated with . . . . (native) Hawaiian ethnicity, residing in a rural area, and, if a woman, coming from a lower income family." Low education attainment, diet and body weight were also mentioned as important factors in diabetes. Native Hawaiians are found in higher concentrations in rural areas; have one of the lowest family incomes and education attainment in the state; maintain unhealthy diets; and have more problems with obesity than other ethnic groups in the State.

E Ola Mau also found that wherever native Hawaiians participate in diabetes screening, they test positive more often than most other ethnic

groups. Diabetes is a principal cause of death among native Hawaiians to the extent that native Hawaiians' diabetes mortality rates were twice the rates of the general population. In addition, diabetes was found to limit the amount and kinds of activity for native Hawaiians more than for non-native Hawaiians.

Besides identifying the problem of diabetes in the native Hawaiian community, E Ola Mau also suggests actions that can be taken to help alleviate the problem. These suggestions are closely aligned with the provisions of Senate Bill 1988. For example, E Ola Mau calls for screening programs that focus on native Hawaiians who have high risk characteristics and prevention programs that can educate native Hawaiians in their health practices, diet, identification of early symptoms and where to seek diagnostic and treatment services. Senate Bill 1988 correspondingly calls for activities to prevent, treat and control diabetes in native Hawaiians; assist in early diagnosis of diabetes; assure proper health care; train health care providers in the prevention, diagnosis and treatment of diabetes; determine appropriate delivery of health care; and develop health education information for native Americans, including native Hawaiians.

These proposed programs are not particularly innovative per se. The manner in which these programs are delivered, however, is extremely crucial. It is the manner of delivery which will determine the successful availability, accessibility and acceptability of the programs. E Ola Mau makes specific recommendations to overcome cultural barriers that may have previously prevented native Hawaiians from receiving health services that could have prevented or treated medical problems such as diabetes. For example, educational programs can be offered in conjunction with existing native Hawaiian organizations which will increase the success of the program by implicitly providing the approval and support of the social environment of the individual. Diabetes screening can be offered on-site in various locations

and at cultural functions where native Hawaiians gather such as native Hawaiian churches, canoe races and civic clubs. Family support can be crucial in helping the diabetic in his follow-up treatments and compliance with medication and diet regimen. Therefore, working with the families as well as native Hawaiian community organizations may be an important aspect of dealing with native Hawaiian diabetics. Another proposed measure for special consideration of native Hawaiians is the training of health care providers to be sensitive to the native Hawaiian culture when dealing with native Hawaiian patients. A better recommendation would be to train native Hawaiians to become health care providers. This measure would increase the number of native Hawaiians in the health care field, in which they are so sorely under-represented, and assure that the health care provider is sensitive to the native Hawaiian. Different aspects of all of the above recommendations can be achieved with the provision of community public health workers who would be native Hawaiians living and working in their own communities. These workers could be instrumental in the education, screening, treatment and monitoring of diabetics in the native Hawaiian community.

SUMMARY

In summary, I would like to reiterate OHA's support for the adoption of Senate Bill 1988. Diabetes is a major health problem in the native Hawaiian community, and this proposed federal legislation would make it possible for native Hawaiians to address this problem in a systematic and meaningful fashion. I would also like to emphasize that in implementing Senate Bill 1988 that special attention be given to the manner in which these programs are delivered. Cultural barriers have to be overcome in the manner of delivery of health care services to native Hawaiians.

The Office of Hawaiian Affairs would like to express its appreciation to this Committee for allowing us the opportunity to provide testimony on this most important subject.

APPENDIX A

[CHAPTER 10]
OFFICE OF HAWAIIAN AFFAIRS

SECTION

[10-1] DECLARATION OF PURPOSE
[10-2] DEFINITIONS
[10-3] PURPOSE OF THE OFFICE
[10-4] OFFICE OF HAWAIIAN AFFAIRS; ESTABLISHED; GENERAL POWERS
[10-5] BOARD OF TRUSTEES; POWERS AND DUTIES
[10-6] GENERAL DUTIES OF THE BOARD
[10-7] BOARD OF TRUSTEES
[10-8] ORGANIZATION; QUORUM; MEETING
[10-9] COMPENSATION; EXPENSE
[10-10] ADMINISTRATOR; APPOINTMENT, TENURE, REMOVAL
[10-11] SALARY OF THE ADMINISTRATOR
[10-12] ASSISTANT; STAFF
[10-13] APPROPRIATIONS; ACCOUNTS; REPORTS
[10-13.5 USE OF PUBLIC LAND TRUST PROCEEDS]
[10-14] BUDGET, AUDITING
[10-15] ANNUAL REPORT
[10-16] SUITS

[§10-1] Declaration of purpose. (a) The people of the State of Hawaii and the United States of America as set forth and approved in the Admission Act, established a public trust which includes among other responsibilities, better-

the public trust entrusted upon the office, either through the office of the attorney general or through private counsel.

(d) In matters involving other forms of remedies, the office, its officers and employees, and the members of the board shall be subject to suit as provided by any other provision of law and by the common law. [L 1979, c 196, pt of §2]

Severability, see L 1979, c 196, §11.

ment of conditions for native Hawaiians. The people of the State of Hawaii reaffirmed their solemn trust obligation and responsibility to native Hawaiians and furthermore declared in the state constitution that there be an office of Hawaiian affairs to address the needs of the aboriginal class of people of Hawaii.

(b) It shall be the duty and responsibility of all state departments and instrumentalities of state government providing services and programs which affect native Hawaiians and Hawaiians to actively work toward the goals of this chapter and to cooperate with and assist wherever possible the office of Hawaiian affairs. [L 1979, c 196, pt of §2]

[§10-2] Definitions. In this chapter, if not inconsistent with the context:

(1) "Office" means the office of Hawaiian affairs;

(2) "Board" means the board of trustees;

(3) "Administrator" means the administrator of the office of Hawaiian affairs;

(4) "Native Hawaiian" means any descendant of not less than one-half part of the races inhabiting the Hawaiian Islands previous to 1778, as defined by the Hawaiian Homes Commission Act, 1920, as amended; provided that the term identically refers to the descendants of such blood quantum of such aboriginal peoples which exercised sovereignty and subsisted in the Hawaiian Islands in 1778 and which peoples thereafter continued to reside in Hawaii;

(5) "Hawaiian" means any descendant of the aboriginal peoples inhabiting the Hawaiian Islands which exercised sovereignty and subsisted in the Hawaiian Islands in 1778, and which peoples thereafter have continued to reside in Hawaii;

(6) "Beneficiary of the public trust entrusted upon the office" means native Hawaiians and Hawaiians. [L 1979, c 196, pt of §2]

[§10-3] Purpose of the office. The purposes of the office of Hawaiian affairs include:

(1) The betterment of conditions of native Hawaiians. A pro rata portion of all the funds derived from the public land trust shall be funded in an amount to be determined by the legislature for this purpose, and shall be held and used solely as a public trust for the betterment of the conditions of native Hawaiians. For the purpose of this chapter, the public land trust shall be all proceeds and income from the sale, lease, or other disposition of lands ceded to the United States by the Republic of Hawaii under the joint resolution of annexation, approved July 7, 1898 (30 Stat. 750), or acquired in exchange for lands so ceded, and conveyed to the State of Hawaii by virtue of section 5(b) of the Act of March 18, 1959 (73 Stat. 4, the Admissions Act), (excluding therefrom lands and all proceeds and income from the sale, lease, or disposition of lands defined as "available lands" by section 203 of the Hawaiian Homes Commission Act, 1920, as amended), and all proceeds and income from the sale, lease, or other disposition of lands retained by the United States under sections 5(c) and 5(d) of the Act of March 18, 1959, later conveyed to the State under section 5(e);

(2) The betterment of conditions of Hawaiians;

(3) Serving as the principal public agency in this State responsible for the performance, development, and coordination of programs and activities relating to native Hawaiians and Hawaiians; except that the Ha-

waiian Homes Commission Act, 1920, as amended, shall be administered by the Hawaiian homes commission;

(4) Assessing the policies and practices of other agencies impacting on native Hawaiians and Hawaiians, and conducting advocacy efforts for native Hawaiians and Hawaiians;

(5) Applying for, receiving, and disbursing, grants and donations from all sources for native Hawaiian and Hawaiian programs and services; and

(6) Serving as a receptacle for reparations. [L 1979, c 196, pt of §2]

[§10-4] Office of Hawaiian affairs; established; general powers. There shall be an office of Hawaiian affairs constituted as a body corporate which shall be a separate entity independent of the executive branch. The office, under the direction of the board of trustees, shall have the following general powers:

(1) To adopt, amend, and repeal by-laws governing the conduct of its business and the performance of the powers and duties granted to or imposed upon it by law;

(2) To acquire in any lawful manner any property, real, personal, or mixed, tangible or intangible, or any interest therein; to hold, maintain, use, and operate the same; and to sell, lease, or otherwise dispose of the same at such time, in such manner and to the extent necessary or appropriate to carry out its purpose;

(3) To determine the character of and the necessity for its obligations and expenditures, and the manner in which they shall be incurred, allowed, and paid, subject to provisions of law specifically applicable to the office of Hawaiian affairs;

(4) To enter into and perform such contracts, leases, cooperative agreements, or other transactions with any agency or instrumentality of the United States, or with the State, or with any political subdivision thereof, or with any person, firm, association, or corporation, as may be necessary in the conduct of its business and on such terms as it may deem appropriate;

(5) To execute, in accordance with its by-laws, all instruments necessary or appropriate in the exercise of any of its powers; and

(6) To take such actions as may be necessary or appropriate to carry out the powers conferred upon it by law. [L 1979, c 196, pt of §2]

[§10-5] Board of trustees; powers and duties. The board shall have the power in accordance with law to:

(1) Manage, invest, and administer the proceeds from the sale or other disposition of lands, natural resources, minerals, and income derived from whatever sources for native Hawaiians and Hawaiians, including all income and proceeds from that pro rata portion of the trust referred to in section 10-3, of this chapter;

(2) Exercise control over real and personal property set aside to the office by the State of Hawaii, the United States of America, or any private sources, and transferred to the office for native Hawaiians and Hawaiians;

(3) Collect, receive, deposit, withdraw, and invest money and property on behalf of the office;

(4) Formulate policy relating to the affairs of native Hawaiians and Hawaiians, provided that such policy shall not diminish or limit the

benefits of native Hawaiians under Article XII, section 4, of the state constitution;

(5) Otherwise act as a trustee as provided by law;

(6) Delegate to the administrator, its officers and employees such powers and duties as may be proper for the performance of the powers and duties vested in the board;

(7) Provide grants to public or private agencies for pilot projects, demonstrations, or both, where such projects or demonstrations fulfill criteria established by the board;

(8) Make available technical and financial assistance and advisory services to any agency or private organization for native Hawaiian and Hawaiian programs, and for other functions pertinent to the purposes of the office of Hawaiian affairs. Financial assistance may be rendered through contractual arrangements as may be agreed upon by the board and any such agency or organization; and

(9) Adopt and use a common seal by which all official acts shall be authenticated. [L 1979, c 196, pt of §2]

[§10-6] General duties of the board. (a) The general duties of the board shall be:

(1) To develop, implement, and continually update a comprehensive master plan for native Hawaiians and Hawaiians which shall include, but not be limited to, the following:

(A) Compilation of basic demographic data on native Hawaiians and Hawaiians;

(B) Identification of the physical, sociological, psychological, and economic needs of native Hawaiians and Hawaiians;

(C) Establishment of immediate and long-range goals pursuant to programs and services for native Hawaiians and Hawaiians;

(D) Establishment of priorities for program implementation and of alternatives for program implementation; and

(E) Organization of administrative and program structure, including the use of facilities and personnel;

(2) To assist in the development of state and county agency plans for native Hawaiian and Hawaiian programs and services;

(3) To maintain an inventory of federal, state, county, and private programs and services for Hawaiians and native Hawaiians and act as a clearinghouse and referral agency;

(4) To advise and inform federal state, and county officials about native Hawaiian and Hawaiian programs, and coordinate federal, state, and county activities relating to native Hawaiians and Hawaiians;

(5) To conduct, encourage, and maintain research relating to native Hawaiians and Hawaiians;

(6) To develop and review models for comprehensive native Hawaiian and Hawaiian programs;

(7) To act as a clearinghouse for applications for federal or state assistance to carry out native Hawaiian or Hawaiian programs or projects;

(8) To apply for, accept and administer any federal funds made available or allotted under any federal act for native Hawaiians or Hawaiians; and

(9) To promote and assist the establishment of agencies to serve native Hawaiians and Hawaiians.

(b) The board shall have any powers which may be necessary for the full and effective performance and discharge of the duties imposed by this chapter, and which may be necessary to fully and completely effectuate the purposes of this chapter. [L 1979, c 196, pt of §2]

[§10-7] Board of trustees. The office of Hawaiian affairs shall be governed by a board to be officially known as the board of trustees, office of Hawaiian affairs. Members of the board shall be elected in accordance with chapter 13D, with reference to sections 11-15, 11-25, 12-5, [and] 12-6, and vacancies shall be filled in accordance with section 17-7. [L 1979, c 196, pt of §2]

Revision Note

Bracketed "and" was added.

[§10-8] Organization; quorum; meeting. The board, at its first meeting after an election, shall elect from its own membership a chairperson and a vice-chairperson who shall serve a term of two years. Their election shall be immediately certified by the board to the lieutenant governor.

A majority of all members to which the board is entitled shall constitute a quorum to do business. The concurrence of a majority of all members to which the board is entitled shall be necessary to make any action of the board valid; provided that due notice shall be given to all members.

Meetings shall be called and held at the call of the chairperson or by a quorum, as often as may be necessary for transaction of the board's business. The board shall meet at least once annually on each of the islands of Hawaii, Maui, Molokai, Lanai, Kauai, and Oahu. [L 1979, c 196, pt of §2]

[§10-9] Compensation; expense. Members of the board shall be allowed:

(1) Compensation at the rate of $50 a day for each day's actual attendance at meeting;
(2) Transportation fares between islands; and
(3) Personal expenses as provided under section 78-15 while attending board meetings on an island other than the island on which their residence is located.

All payments for compensation, travel, and expenses shall be paid by warrants signed by the chairperson of the board. [L 1979, c 196, pt of §2]

[§10-10] Administrator; appointment, tenure, removal. The board by a majority vote, shall appoint an administrator who shall serve without regard to the provisions of chapters 76 and 77 for a term to be determined by the board. The board, by a two-thirds vote of all members to which it is entitled, may remove the administrator for cause at any time. [L 1979, c 196, pt of §2]

[§10-11] Salary of the administrator. The salary of the administrator shall be $30,000. The administrator shall be included in any benefit program generally applicable to officers and employees of the State. [L 1979, c 196, pt of §2]

[§10-12] Assistant; staff. The administrator may employ and retain such officers and employees as may be necessary, subject to the approval of the

board, to carry out the functions of the office. Such officers and employees may be hired without regard to chapters 76 and 77, and shall serve at the pleasure of the administrator. Officers and employees of the office of Hawaiian affairs shall be included in any benefit program generally applicable to officers and employees of the State. [L 1979, c 196, pt of §2]

[§10-13] Appropriations; accounts; reports. Moneys appropriated by the legislature for the office shall be payable by the director of finance, upon vouchers approved by the board, or by any officer elected or appointed by the board and authorized by the board to approve such vouchers on behalf of the board. All moneys received by or on behalf of the board shall be deposited with the director of finance and kept separate from moneys in the state treasury; except that any moneys received from the federal government or from private contributions shall be deposited and accounted for in accordance with conditions established by the agencies or persons from whom the moneys are received; and except that with the concurrence of the director of finance, moneys received from the federal government for research, training, and other related purposes of a transitory nature, and moneys in trust or revolving funds administered by the office, shall be deposited in depositories other than the state treasury. Income derived from the sale of goods or services and income from lands and property as described in section 10-3, shall be credited to special or other funds; provided that upon the recommendation of the office, the comptroller shall establish such other separate accounts or special funds for other designated revenues as may be directed by the board or its authorized representative. [L 1979, c 196, pt of §2]

[§10-13.5 Use of public land trust proceeds.] Twenty per cent of all funds derived from the public land trust, described in section 10-3, shall be expended by the office, as defined in section 10-2, for the purposes of this chapter. [L 1980, c 273, §1]

[§10-14] Budget, auditing. The board shall annually submit a proposed budget for the office to the legislature. The office shall be subject annually to government audit. [L 1979, c 196, pt of §2]

[§10-15] Annual report. The board shall prepare and make public their annual report which shall include an enumeration of their activities, income, and expenditures during the year. The annual report shall be submitted to the governor and the legislature ten days prior to the convening of each regular session of the legislature. The board shall prepare and submit special reports as may be required by the legislature. [L 1979, c 196, pt of §2]

[§10-16] Suits. (a) The office may sue and be sued in its corporate name. The State shall not be liable for any acts or omissions of the office, its officers, employees, and the members of the board of trustees, except as provided under subsection (b).

(b) In matters of tort, the office, its officers and employees, and the members of the board shall be subject to suit only in the manner provided for suits against the State under chapter 662.

(c) In matters of misapplication of funds and resources in breach of fiduciary duty, board members shall be subject to suit brought by any beneficiary of

APPENDIX B

E OLA MAU

THE NATIVE HAWAIIAN HEALTH NEEDS STUDY

MEDICAL TASK FORCE REPORT

The Native Hawaiian Health Research Consortium

ALU LIKE, INC.

Honolulu, Hawaii

December 1985

V. DIABETES: EPIDEMIOLOGY AND HEALTH CARE

A. EPIDEMIOLOGY OF DIABETES

Prevalence of Morbidity

As presented in Chapter III of this report on the prevalence and distribution of diabetes in the general population, it is one of the most prevalent chronic conditions. In fact in Table III-9 in Chapter III, which shows the rankings of age-adjusted rates of different chronic conditions, diabetes is ranked tenth overall. For Native Hawaiians, however, it was ranked fifth most prevalent. If we look at the subgroups of Native Hawaiians, we see that for Hawaiians it is the third most prevalent chronic condition as compared to fifth for Part-Hawaiians. Thus, diabetes is one of the most prevalent chronic conditions in the population. For Native Hawaiians it is even more prevalent than for the general population of the state. Within the Native Hawaiian group, Hawaiians suffer from diabetes much more frequently than Part-Hawaiians.

If we compare specific ethnic/racial groups in Table III-10 in Chapter III, we see that diabetes is ranked high overall in terms of prevalence. Hawaiians are ranked number one, Native Hawaiians number two, and Part-Hawaiians number three in age-adjusted prevalence rates. Thus, compared to other ethnic/racial groups, Native Hawaiians and the sub-categories: Hawaiians and Part-Hawaiians, have the highest prevalence of any other groups. The above findings are valid for the most recent years, 1980-84, for which prevalence data are available.

If we look at the age and sex distribution of diabetes within the Native Hawaiians (see Table III-8,in Chapter III) we see that as

the age increases, the prevalence rates for diabetes increase. For Part-Hawaiians, female prevalence is higher than male, but for Hawaiians male prevalence is higher than female prevalence. For Native Hawaiians, which includes both Hawaiian and Part-Hawaiian, female prevalence is higher than male. For the general population, females are higher than males and older persons higher than younger persons in prevalence of diabetes. Thus, the overall findings for Native Hawaiians is similar to the general population in this espect.

A study of diabetes during the period 1974-76 indicates that, "...increased frequency of diabetes appears to be associated with age over 45, Hawaiian ethnicity, residing in a rural area, and, if a woman, coming from a lower income family" (Varney, 1979). This agrees with the 1980-84 findings in Tables V-1 and V-2 which show diabetes prevalence rates by geographic area and education for each ethnic group. Table V-1 shows that overall rural residents have higher rates of diabetes than urban. This is true for Hawaiians as a rule; however, for Part-Hawaiians there are urban areas such as Honolulu where the diabetes rates are higher than for rural areas. The rates in this table have not been age-adjusted and, therefore, may reflect the differences in age between the rural and urban populations. For example, rural populations are generally younger than urban populations and since diabetes affects the older population more, one might expect the urban popultion to have higher rates. This is so for Honolulu. Molokai is rural and the rates are lower there for Part-Hawaiians. The Hawaiian group is generally older than the Part-Hawaiian group and overall has higher rates of diabetes and also generally has higher rates in the rural areas than

urban areas.

The relationship between diabetes and education shows that those with less than 12 years of completed education have higher rates of diabetes than those with more education. Diabetes appears to be a disease of those who have less education. This is true for Native Hawaiians as well as for other ethnic groups.

Table V-3 shows those who have diabetes are most likely to have seen a doctor within the past 6 months.

In addition, the annual statistics from the Chronic Disease Branch of the Hawaii State Department of Health (Department of Health Annual Report, 1968 through 1984) indicate that Native Hawaiians have historically been among the highest groups in terms of the proportion of screenees who test positive on diabetes tests, and among the highest groups in terms of percentage of new diabetics of those screened. Even though the screenings are not a representative sample of the total population, it does indicate that Native Hawaiians, wherever they participate in diabetes screening, do test positive more often than most other groups.

In addition to the above socio-demographic factors associated with prevalence of diabetes, some of the Hawaii State Department of Health and Diabetes Association literature on diabetes indicate that diet and body weight are important factors in diabetes, although the actual causes of diabetes are unclear.

Mortality Caused by Diabetes

In addition to consideration of the prevalence and distribution of diabetes within the general population and among Native Hawaiians, it is also important to consider diabetes as a cause of death. As indicated above, however, diabetes mortality rates may

underestimate its true effect since it may contribute to other conditions such as arteriosclerosis and renal failure from which the person is more likely to die and which would be recorded as the principal cause of death rather than diabetes. Thus, its true impact on mortality statistics is understated when considering it only as the principal or immediate cause of death. Even so, as we will see below, diabetes as a principal cause of death is among the top causes of death for the population as a whole and among Native Hawaiians (see Tables III-1 and III-2). In fact, for Part-Hawaiians it is the most important cause of death, as it is for non-Hawaiians. In comparing diabetes as a cause of death among Native Hawaiians, it is a more important cause of death for Part-Hawaiians than for Hawaiians (see Table III-3). Part-Hawaiians have higher age-adjusted mortality from diabetes than do other non-Hawaiian groups.

A recent study done on historical trends in diabetes mortality in Hawaii shows that since 1910 Native Hawaiians have had the highest mortality from diabetes as compared with other non-Hawaiians (Look, 1982). This study indicated that in 1910, within the Native Hawaiian category, Hawaiians were more numerous and Part-Hawaiians less numerous. Since then, Part-Hawaiians are more numerous than Hawaiians by a ratio of 1 to 20. Figure V-1 was taken from the Look study, mentioned above. It shows the trends in mortality rates from diabetes from 1910 to 1980. As we can see, the overall trends were increasing until 1960 and decreasing from 1960 to 1980. For Hawaiians, the trends show a sharp increase from 1910 to 1960 and then a leveling off from 1960 to 1970 and then a decline from 1970 to 1980. The Part-Hawaiian trends rose from 1910 to 1920 then fell

sharply from 1920 to 1930, then increased moderately from 1930 to 1950 and have declined moderately from 1950 to 1980. In 1980 the Hawaiians' diabetes mortality was twice the rates for Part-Hawaiians, and Part-Hawaiians in turn were twice the rates of the general population, even though overall rates in 1980 were lower than they had been since the 1950-1960 period.

Limitation of Activity

The extent to which a chronic condition limits the amount or kinds of activity a person may engage in, particularly when it prevents the person from engaging in major activity, is an important indicator of the effect of the condition upon the person's quality of life. This contrasts with mortality which is an indicator of the length of life. The HSP Health Survey obtains information on the extent to which a reported illness limits the person's amount or kind of usual activities. It also obtains information on the person's major activity, be it work, keeping house, going to school and the like. The person is asked if diabetes (if they report that they have diabetes) prevents them from engaging in their major activity. The responses to this question are summarized by ethnicity in Table III-11. Of those who have diabetes, 7.9% say that it limits their ability to engage in their major activity. For Native Hawaiians 10.6%, Hawaiians 9.1% and Part-Hawaiians 10.9%. Thus, diabetes is more limiting for Native Hawaiians than for non-Hawaiians and for Part-Hawaiians than Hawaiians.

In terms of limitation of activity in general (including major activity), some 26% of the general population find that diabetes causes them to cut down on the things they usually do (see Table III-12). Some 28.1% of Native Hawaiians, 27.9% of Part-Hawaiians

and 29.5% of Hawaiians who have diabetes say it causes them to cut down on the things they usually do. This means that, compared to the general population, a greater proportion of Native Hawaiians have to cut down on their usual activities due to diabetes. Since Hawaiians are generally older than Part-Hawaiians as a group, it is natural to expect that diabetes would tend to limit their activities more. However, as shown above, the Part-Hawaiians experienced a greater percentage of not being able to engage in their major activity compared to Hawaiians. This may be due to the fact that more Part-Hawaiians, being younger, consider their major activity to be work. Thus, diabetes would tend to prevent them from working more than for the older group of Hawaiians who may not work as much.

In ranking diabetes on the percentage of persons who report the condition as causing them to limit their usual activities, Table III-13 shows for Native Hawaiians that diabetes is third, Hawaiians are second and Part-Hawaiians are fourth. Caucasians and Japanese experience more limitation than the Hawaiian groups. Other goups such as Filipino and Chinese and "Other" have less limitation due to diabetes than do the Native Hawaiians. These findings are supported by a study of diabetes for 1974-76 (Varney, 1979), where Hawaiians ranked second only to Caucasians in percentage activity limitation due to diabetes.

Diabetes, therefore, causes some limitation of usual activity and prevents some from working or engaging in their major activity. Hawaiians, overall, suffer more from these limitations or effects of diabetes than does the population in general.

Literature from research, control and treatment organizations

for heart and kidney disease indicate that some of the secondary conditions arising out of diabetes are renal failure, arteriosclerosis, retinopathy and problems with circulation in the extremities and healing of wounds.

Unfortunately, information on the incidence of diabetic shock, hopitalization, physician office visits, and other indicators of impact or effects of diabetes are not readily available. These are areas which require additional consideration in further research on diabetes.

Implications of Epidemiological Findings for Locating a Target Population for Services

As indicated above, Native Hawaiians have the highest diabetes rates of any group in Hawaii, and therefore are a prime target group for additional study and for planning services. Subpopulations of Native Hawaiians are also identified as being targets for services and these persons are women, older population, rural residents and persons with low income. These identify the characteristics of high risk persons and the more of these characteristics a person has, the greater the risk of them either having diabetes or in eventually having it. Therefore, it seems that screening programs might focus on Native Hawaiians who have these high risk characteristics in an attempt to identify persons who already have undetected diabetes. In addition, prevention programs should focus on Native Hawaiians, particularly those who have these characteristics, in an attempt to educate them in their health practices, diet, and in how to identify early symptoms and where to seek diagnostic and treatment services in their communities. There can be an effort to assure adequate treatment services in areas where Native Hawaiians live and to educate providers of care to be alert to symptoms among the high

risk groups and to do screening of these groups on a routine basis when these persons come in for routine physical examinations or when they come in for other services.

B. HEALTH SERVICES: AVAILABILITY, ACCESSABILITY AND ACCEPTABILITY

Availability of health services for diabetes patients is determined by the distribution of professional medical practitioners and facilities. Accessability is a function of location, time and payment for services. Acceptability of services is determined in part by cultural attitudes toward services.

There is some indication in some chronic illnesses such as cancer and diabetes that oftentimes Native Hawaiians are diagnosed with these illnesses at later stages, when the illness has progressed to a point where it is difficult to treat. This is due at least in part to either resistance in seeking treatment even when some morbid symptoms exist. It may also be due to lack of services or inconvenience in terms of time, distance or cost in getting diagnostic and treatment services. Where a person lives in remote areas, does not have health insurance, or may not feel the necessity of having regular medical check-ups or in participating in screening programs, then it is likely that they will not discover the presence of a morbid condition until the symptoms become pronounced and perhaps debilitating.

For example, with many patients the gradual loss of eyesight motivates the search for eye care, whereupon the practitioner finds the person has had a history of diabetic symptoms and now is suffering from some of the effects of a severe eye disorder called diabetic retinopathy. Had the diabetes been diagnosed and treated early, it could have been arrested and there would have been no loss

of eye function. Oftentimes, when retinopathy has been diagnosed, it has progressed to the point where some or all of the person's eyesight is in jeopardy.

In order to prevent such examples, it is important to have health education and promotion programs as well as screening and referral progrms for diabetes. The Diabetes Association and the Chronic Disease Branch of the Hawaii State Department of Health are two organizations dedicated to health education and prevention of diabetes. These two organizations conduct diabetes screening and referral at different sites throughout the State. The statistics on the characteristics of persons they screen and the results of the screening are published in the Department of Health Annual Report. The screening program has been expanded to include 10,000 persons during 1985. This screening will probably include only some 800-1000 Native Hawaiians at most. Therefore, it is inadequate as a tool for screening the Native Hawaiians since, if one were to include the high risk Native Hawaiians, one should attempt to screen all women age 45 and over, particularly those living in low income and rural areas. Oftentimes these are the very areas which are excluded from typical screening programs because of inaccessability and cost.

Another aspect of treatment of diabetes is the willingness of patients to follow a strict diet and to observe a strict schedule of medication and monitoring. This requires that the patient be motivated and that members of the family be supportive. It also requires some adjustment in the patient's working, social, family and other daily activities. If a patient has been reluctant to observe preventive measures or in seeking diagnostic and treatment

services then it is unlikely that once, they are diagnosed with diabetes, they will willingly comply to the diet and medication schedules required of diabetics.

Compliance is one of the most difficult problems of diabetics and requires constant monitoring by health providers as well as constant support of the patient's family. There is some evidence that Native Hawaiians find compliance a particular challenge since it violates many cultural practices. If this is true, special educational and motivational efforts must be available to Native Hawaiians in order to facilitate the prevention, diagnosis and treatment of diabetes.

C. SUMMARY

The above description of the epidemiology of diabetes among Native Hawaiians has shown that, in terms of morbidity and mortality, Native Hawaiians experience higher rates than the general population, if not higher rates than any other racial/ethnic groups in Hawaii. Among Native Hawaiians, females, rural residents, low income and those over age 45 are at highest risk of having diabetes.

In terms of the effects of diabetes upon Native Hawaiians there appears to be greater activity limitation than that suffered by the population in general. Native Hawaiians are typically diagnosed with diabetes at later stages of the illness and, therefore, suffer more severe effects such as renal failure, arteriosclerosis, loss of circulation in the extremities and retinopathy, more so than other groups who seek diagnostic and treatment services earlier.

There needs to be an effort to provide education, screening, diagnosis and treatment programs for diabetes for Native Hawaiians in culturally acceptable ways within local communities and within

groups with which Native Hawaiians are affiliated. Providers of care should be aware of the high risks of Native Hawaiians and routinely provide screening and prevention for those at risk in a culturally appropriate manner. Treatment must address the problems associated with compliance with diet and medication requirements of diabetes among Native Hawaiians.

D. RECOMMENDATIONS

The first recommendation would be to augment the existing screening programs for diabetes done by the Diabetes Association and the Chronic Disease Branch of the Hawaii State Department of Health to include subpopulations of Native Hawaiians who suffer high risk of diabetes. This of course will require funding beyond the level now available. It will require additional staffing to do the screening and to assure adequate follow-up to make sure that positive screenees receive treatment.

Additional educational programs by the Health Promotion and Education Office of the Department of Health in conjunction with various Hawaiian organizations in local areas can be implemented and perhaps coordinated with the screening program to publicize the need for prevention and for regular check-ups and screening. It might be possible to conduct some screening on site at various locations where Native Hawaiians gather, or within the context of specific Hawaiian organizations such as civic clubs, churches, etc.

The providers of medical care in the community need to be motivated to be sensitive to Hawaiian culture in dealing with Native Hawaiian patients and also be alert to those who are at risk to carefully check reports of symtoms of early stages of diabetes, and also to provide diagnostic and screening tests along with routine

visits and check-ups of high risk persons. Providers must also be sensitive to Hawaiian culture in trying to motivate patients who have diabetes to comply with diet and medication regimens. This may require working with the families as well as with community leaders.

One of the most effective ways of implementing screening, diagnosis and treatment programs among Native Hawaiians for diabetes might be through community public health workers who live with and may, in fact, be Native Hawaiians themselves. These persons can work with Hawaiian leaders, kahunas, kapunas, and the ohanas to gain confidence and knowledge of their situation and to become aware of various health problems and to encourage them to be aware of, and observe, healthful practices consistent with Hawaiian culture and to utilize the western medical and health system to prevent as well as diagnose illness, specifically illnesses such as diabetes. They can also perform some of the education on prevention and screening and some initial or follow-up treatment and encouragement to observe dietary and medicinal regimens.

The creation of such a cadre of public health workers will require considerable seed money to select and educate them and then to pay them. Such resources could initially be provided by Federal funding with some State matching funds. This ratio could shift over a period of five to ten years with a greater load assumed by state and private local funds as the program takes hold. The evaluation of the effectiveness of such a program could be done annually to determine its ability to achieve the stated objectives. The program can be implemented for diabetes as well as all other high prevalence illnesses of Native Hawaiians.

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TABLE V-1, RATES(PER 1000) OF SELECTED CHRONIC CONDITIONS BY AREA AND ETHNICITY, HAWAII 1980-84

DIABETES AREA	TOTAL	CAUC-ASIAN	JAPAN-ESE	NATIVE HAW'N	HAW-IIAN	PART HAW'N	FILI-PINO	CHIN-ESE	OTHER/ UNK'WN
STATE	20.5	15.3	31.5	19.3	69.3	17.0	20.3	31.9	11.8
OAHU	19.1	13.7	28.0	20.0	59.2	18.3	18.1	30.9	11.4
HONOLULU	24.6	18.0	33.4	28.8	51.9	27.6	18.7	29.2	13.3
CENTRAL OAHU	13.9	8.7	21.8	10.9	56.7	9.8	16.7	42.1	9.3
WAIANAE	19.6	36.5	20.1	15.7	68.3	11.2	21.7	0.0	15.4
WINDWARD	17.3	13.2	20.8	22.2	68.2	21.0	27.2	22.3	12.2
HAWAII COUNTY	23.1	22.2	32.1	17.0	88.8	12.5	28.1	51.7	15.8
KAUAI COUNTY	30.7	25.2	58.6	20.7	127.6	17.1	26.1	42.0	12.1
MAUI COUNTY	25.8	18.6	52.7	17.7	72.5	14.2	25.1	61.9	11.5
MAUI	25.1	18.2	52.3	17.3	65.2	13.6	21.8	64.7	9.3
MOLOKAI	20.5	23.3	43.1	19.2	44.6	16.5	18.7	66.7	7.0
LANAI	64.1	48.9	69.6	29.9	0.0	31.4	64.6	0.0	95.4

SOURCE: Health Surveillance Program, State Department of Health

TABLE V-2, RATES(PER 1000) OF SELECTED CONDITIONS BY EDUCATION AND ETHNICITY, HAWAII 1980-84

DIABETES EDUCATION	TOTAL	CAUC-ASIAN	JAPAN-ESE	NATIVE HAW'N	HAW-IIAN	PART HAW'N	FILI-PINO	CHIN-ESE	OTHER/ UNKNWN
NONE	3.8	0.1	9.2	0.5	29.8	0.1	15.7	29.3	1.4
1 - 11 YRS	80.0	66.4	131.1	64.9	201.9	56.3	86.1	105.7	45.3
HIGH 12 YEARS	23.9	15.9	35.5	23.2	61.3	20.9	20.5	39.3	17.1
VOCATIONAL	25.7	16.0	26.6	24.8	0.0	26.2	21.2	76.0	13.1
COLLEGE 13-15 YRS	13.5	11.2	19.6	16.4	0.0	17.0	6.3	21.6	7.7
COLLEGE 16 YEARS	15.3	14.7	13.8	15.8	68.5	13.3	20.1	17.8	15.6
POST GRADUATE	16.4	14.4	17.6	14.1	100.0	11.8	23.1	15.1	24.0
UNKNOWN	23.6	26.4	32.5	42.4	144.4	29.5	13.7	52.9	0.9
TOTAL	20.5	14.1	31.5	19.3	69.3	17.0	20.3	31.9	11.8

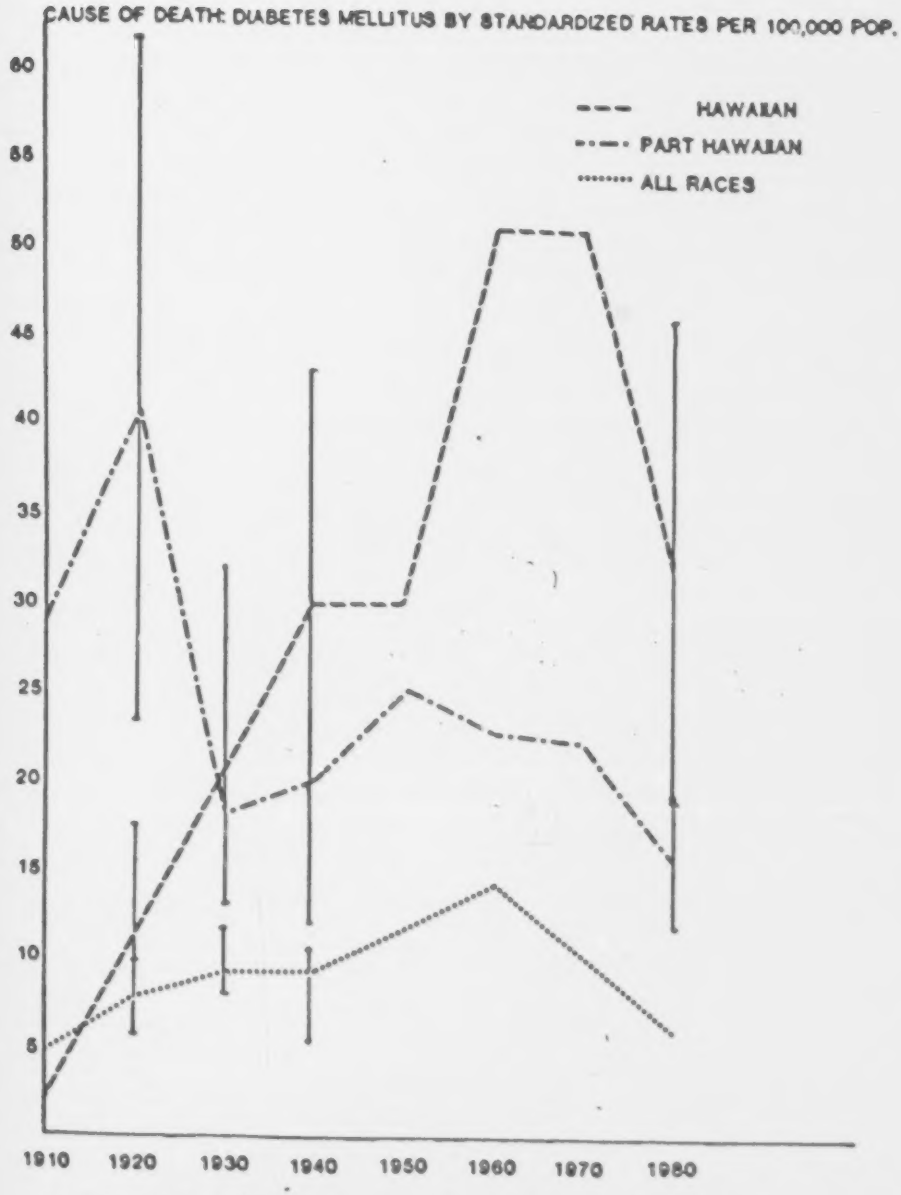
SOURCE: Health Surveillance Program, State Department of Health

TABLE V-3, RATES(PER 1000) OF CONDITIONS BY TIME SINCE SAW DOCTOR AND ETHNICITY, HAWAII 1980-84

DIABETES TIME SINCE SAW DR	TOTAL	CAUC-ASIAN	JAPAN-ESE	NATIVE HAW'N	HAW-IIAN	PART HAW'N	FILI-PINO	CHIN-ESE	OTHER/ UNKNWN
NONE	0.1	0.1	0.1	0.1	0.0	0.1	0.1	0.7	0.1
WITHIN 6 MONTHS	18.1	13.1	28.3	17.4	388.5	3.0	24.6	42.9	7.5
6 MONTHS & OVER	2.2	1.9	3.0	1.8	6.1	1.4	2.8	4.0	0.9
UNKNOWN	0.1	0.1	0.1	0.0	0.0	0.0	0.0	0.0	0.1
TOTAL	20.5	15.3	31.5	19.3	69.3	17.0	20.3	31.8	11.8

SOURCE: Health Surveillance Program, State Department of Health

Figure V-1



Source: "A Mortality Study of the Hawaiian People," by Mele A. Look, Student, Department of American Studies, University of Hawaii, R & S Report Issue #38, February 1982.

PREPARED STATEMENT OF DR. DAVID JOHNSON

Senator Andrews and members of the Senate Select Committee on Indian Affairs, I am David Johnson, testifying in support of S.1988 on behalf of the Hawaiian Health Research Consortium (HHRC). This Consortium is coordinated by ALU LIKE and includes members from Native Hawaiian institutions and agencies and from public and private research, educational and health institutions and agencies.

A Native Hawaiian Health Needs Study was recently completed by the HHRC. This Study was supported through a Senate directive to the DHHS to conduct a comprehensive health needs study of Native Hawaiians. I was the Principal Investigator of this Study. Native Hawaiians are defined in this Study as "any individual, any of whose ancestors were natives of this area which consists of the Hawaiian Islands prior to 1778."

In reference to Section 2(a) of the Bill, findings from this Study (as shown in Attachment A) indicate that Native Hawaiians experience a substantially higher incidence and prevalence of diabetes than do other ethnic groups in Hawaii. This is true for each age and gender category as well as area of residence in Hawaii. In comparison to other chronic conditions, diabetes ranks fifth in prevalence for Native Hawaiians compared to tenth for the general population of the State of Hawaii.

Native Hawaiian rates of diabetes are three to four times higher than that of the general population of the State. There is some evidence that these rates are underreported and that, due to lack of participation in ongoing screening programs, the Native Hawaiian diabetes rates are perhaps more under-reported than for other groups. In fact, there are estimates that, for the general American population, some 40% of those who have diabetes are not aware that they have it (see Attachment B). Native Hawaiians are diagnosed with diabetes at later stages of the disease than the general population because of the unavailability of and/or reluctance to obtain regular medical checkups. Medical help is not sought unless severe symptoms exist, which means that for many Native Hawaiians the effects of diabetes are irreversible and catastrophic. This translates into higher proportions of Native Hawaiians suffering from retinopathy, end-stage renal disease, gangrene, and arteriosclerosis than experienced by the general population of the State. It also means that the costs both in terms of suffering and expenditures of economic and medical resources are higher.

The State of Hawaii has twice the number of persons with end-stage renal disease (ESRD) per population as the Nation. And within Hawaii, Native Hawaiians are over-represented in this category of illness by a factor of two. The percentage of ESRD patients with diabetes is steadily increasing. In 1984 about 28% of new ESRD patients in Hawaii had a primary cause of diabetes, and in 1985 the percentage has grown to 38%. Diabetes makes it more likely for an ESRD patient to have complications, such as problems with vascular abcess, infection, amputation of limbs, retinopathy and blindness. It also means that they are poor candidates for kidney transplantation. The diabetic patient suffers more inpatient hospitalizations. This translates into poorer prognosis, lower quality of life, less opportunity for participation in normal social and economic activities, such as work, family life and so forth. It also means that the dollar costs are higher and the social, economic and medical resource costs are higher for Native Hawaiians suffering from ESRD than for other patients due to their having more diabetes.

It is felt that the provisions of this Bill for determining the cause of diabetes, developing early diagnosis and treatment and prevention to reduce the incidence of diabetes, and training of Native Hawaiian providers in diagnosis, treatment and control of related complications are urgently needed. It is particularly important to provide for community based educational and outreach programs for prevention and treatment since these will be sensitive to the cultural values and needs of Native Hawaiians.

In reference to Section 2(b), the strengthening or broadening of diabetes research and related complications is urgent. It is important that small area data be generated for Native Hawaiians. State and local area participation of Native Hawaiian organizations and individuals is important both in data collection, and also for the purpose of building Native Hawaiian research capability and participation in planning and implementation of plans for development, implementation and evaluation of diabetes prevention and control programs.

Section 3(a) refers to a study on diabetes among Native Hawaiians to be conducted by DHHS. Such a study, while federally-funded and supervised, can best be accomplished through cooperative arrangements with local Native Hawaiian agencies and organizations. While the Hawaiian Health Needs Study, referred to previously, was a step in the direction of accomplishing such a goal, it was only a beginning. Additional efforts need to be made to determine the true prevalence of diabetes. Additional research, which will identify specific sub-groups of Native Hawaiians at high risk in order to target screening, educational and prevention programs, are needed. This will help to mobilize Native Hawaiian organizations in local areas to participate in these research, screening, educational and prevention and treatment programs.

Existing health and medical personnel and facilities, along with existing Native Hawaiian community organizations, can provide expertise and other support both in research and also in implementation. This kind of cooperation between Native Hawaiian groups and existing medical/health professionals and facilities will provide greater cultural sensitivity and success in research and in implementation of the research findings among the Native Hawaiians.

Such a cooperative venture will also strengthen the Native Hawaiian interest and capability to conduct research and to plan and implement prevention and treatment programs within the Native Hawaiian population. This fosters on-the-job training as well as interest in acquiring formal training in these areas. It also fosters greater awareness and interest along with community support for such programs. It fosters self- sufficiency and pride in accomplishment and ultimately it fosters improved health of Native Hawaiians.

In reference to Section 4(a), it is seen as most appropriate to provide for the diagnosis, treatment and care of Native Hawaiians with diabetes within the context of cultural values and practices. Since the prevention and control of diabetes requires patient-specific awareness and cooperation, it is essential to involve local Native Hawaiian organizations and leaders in these prevention and control programs, because it is these organizations and leaders to whom Native Hawaiians turn for advice and guidance on health matters. Community health centers as well as providers of specialty care need to work cooperatively with Native Hawaiian community based organizations to provide linkage with the Native Hawaiian population. This can be done most effectively through the enhancement and creation of local prevention and treatment programs which are community-based and operated cooperatively with Native Hawaiian organizations and leaders within the Native Hawaiian cultural context. This will enable the mobilization of community resources, community concern and awareness and will enable the prevention and treatment programs to achieve their goals.

In reference to Section 5, it is important to develop a standardized, comprehensive system of collecting, analyzing, and reporting data regarding diabetes and related complications for Native Hawaiians. Again, as mentioned previously, such a system can best be accomplished through cooperative efforts with existing Native Hawaiian organizations experienced in this kind of research. This will facilitate such an effort and will enable development of research, analysis and data management capabilities at the local level within the Native Hawaiian community. This will foster greater self-reliance and capability in data collection, interpretation and use and will also enable quality nationwide data for Native Americans.

In reference to Section 6, such research should be coordinated with Native Hawaiian organizations in order to provide for enhancement of research capabilities and also to provide for community support and interest in research impacting Native Hawaiians. This will facilitate the use of research findings, better planning and more effective implementation of recommendations and programs to prevent and control diabetes in the Native Hawaiian popualtion.

In summary, in order to assure the success of program planning and implementation for the prevention and control of diabetes among Native Hawaiians, it is important to involve Native Hawaiian agencies and organizations. This will enhance the involvement and expertise of Native Hawaiians in the research and control of diabetes and will also assure acceptance and participation of Native Hawaiians in planning for, and implementing programs, to prevent and control diabetes individually and collectively. It will also enhance the Native Hawaiian's feeling of responsibility for their own health and well-being within a culturally appropriate and acceptable environment.

To this end, the Hawaiian Health Research Consortium and the agencies and organizations represented therein are supportive of the provisions of Senate Bill 1988 to establish a program for the prevention and control of diabetes among Native Americans.

Thank you for giving us the opportunity to make this presentation.

PREPARED STATEMENT OF CALEB SHIELDS

Mr. Chairman and members of the Committee, my name is Caleb Shields. I am a member of the Tribal Executive Board of the Assiniboine and Sioux Tribes of the Fort Peck Reservation. With me today is Kenneth Smoker, also of the Executive Board. It is indeed a pleasure to testify before the Committee concerning S.1988, a bill to establish a program for the prevention and control of diabetes among Native Americans.

Next to abuse of alcohol, diabetes is the number one health problem on the Fort Peck Reservation. Diabetes shortens lives and can cause blindness, loss of limbs, and other serious disabilities. The high incidence of alcoholism increases the problems with diabetes, because alcoholic diabetics frequently do not control their diets, monitor their blood sugar levels, and take the proper medication.

Diabetes is also a very expensive problem. It puts a tremendous strain on every component of the IHS and tribal health budgets. To give just one example, we have fifteen diabetics on the Reservation who need kidney dialysis. This

number has more than doubled over the past two years. Medicare bears a portion of this cost and the Tribes pick up the rest, including needed support services. Over the past three years, the Tribes have spent $192,000 on kidney dialysis and related services.

The Fort Peck Tribes believe that this terrible situation could be significantly improved through an expanded federal program to combat diabetes. The Tribes therefore strongly support S.1988. The Tribes thank Senator Melcher and the other sponsors of the bill for introducing this much-needed legislation. The bill takes a comprehensive approach to the problem of diabetes -- it seeks to improve research and data collection as well as prevention and treatment.

There are several portions of the bill for which we would like to express particular support. Diabetes is an excellent target for health promotion and disease prevention efforts. Even difficult cases can often be controlled through diet, monitoring, and other health promotion efforts. Borderline cases can essentially be prevented altogether. And, through proper education, potentially diabetic young people can develop the habits early in life that will avoid severe problems later on.

Given these facts, we strongly support Sections 4(a)(3), (a)(5), and (a)(6) of the bill. These sections would require IHS to train federal and tribal health care providers in diabetes prevention and control, develop health education materials on diabetes for Indian communities and schools, and provide proper follow-up care for Indian diabetics. These programs will help control severe cases of diabetes and stop other cases before they get started. They will also save money in the long run, because prevention is much less expensive than hospitalization and other forms of direct medical treatment.

We at Fort Peck have heard excellent reports concerning the IHS model diabetes programs. We therefore support Sections 4(c)(1) and (c)(2) of the bill, which would continue the existing programs and require IHS to establish five more such programs, including one in Montana. However, even more important is Section 4(c)(3), which would require IHS to assure that the knowledge and benefits gained from the existing model diabetes programs be made available to all service units. IHS has enough experience with these model programs by now that the diabetes program at every service unit should be similar to the model programs.

I would like to express two concerns about the bill. First, it is the Indian people who suffer from this terrible disease in such high numbers. We believe that we have unique

knowledge of diabetes and the social problems that make prevention and control of this disease so difficult. The Fort Peck Tribes therefore request that in undertaking the activities required by Section 4 of the bill, IHS be required to consult with tribes and tribal health contractors, and to take into account tribal specific health plans. We attach language that would accomplish this change.

S.1988 would add Native Hawaiians to the IHS service population for purposes of diabetes programs. To the extent that diabetes is a severe problem for Native Hawaiians, the Fort Peck Tribes support federal assistance for this group. However, we are also concerned about placing additional stresses on IHS, which already has limited resources. As a compromise, we suggest that Native Hawaiians be deleted from this bill, and that their needs with respect to diabetes be addressed within S.2243, the Hawaiian-specific health bill.

Finally, I would like to say a few words about the Administration's position on this bill. The Administration opposes the bill, in part because it might result in deduction of funds from other, "higher priority" activities. The Tribes find it difficult to believe that there are activities of higher priority than prevention, control and treatment of diabetes. And, even if S.1988 would require diversion of funds from other programs at current funding levels, the IHS response

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should be to request more funds. This would be a welcome change from the outrageous cuts that the Administration requests every fiscal year.

That concludes my testimony for today. I would be happy to answer any questions you may have.

Amendment concerning tribal participation

Amend Section 4 of S.1988 to add a new subsection (f) as follows:

> (f) In developing and implementing the programs required by Section 4 of this Act, the Secretary shall consult with tribes and tribal health contractors, and shall also consult the tribal specific health plans.

PREPARED STATEMENT OF JOHN BUFFALOHORN

I. Description of the Northern Cheyenne Reservation

The Northern Cheyenne Reservation is located in a remote section of southeastern Montana in Rosebud and Bighorn counties. The nearest metropolitian area, Billings, Montana, is approximately one hundred miles away from the reservation. Travel to and from Billings via Highway 212, a single lane highway, is often treacherous and risky due to the general poor condition of the road, coupled with a large volume of truck traffic.

The Northern Cheyenne Reservation is located on approximately 144,000 square acres of land. The general size of the reservation is twenty-three miles by forty-eight miles. Altitude levels range from 3,000 to 5,000 feet above sea level. The 3,000 foot level offers smooth, treeless, rolling hills; the central region of the reservation is characterized by upland plateaus deeply dissected by the Tongue River and Rosebud Creek and their tributaries; the 5,000 foot level offers heavily wooded (Ponderosa Pine), low mountain sites, dotted with fresh-water ponds and lakes.

The regional climate of the reservation is continental/semi-arid. Average temperatures range from 25 F in the winter months to 75 F in the summer months; extreme temperatures range from -40 F in the winter to 100 F in the summer. Although these temperatures appear harsh, the region has a low humidity factor making climatic conditions more tolerable. The precipitation averages 14 to 18 inches of moisture a year.

According to current health care statistics provided by the Northern Cheyenne Tribal Health Department, there are approximately 5,100 individuals eligible to receive health care services provided by the Tribal Board of Health and the

PHS Indian Health Service. The figure includes tribal enrolled members and other eligible Indians living on or near the reservation.

II. History of Diabetic and Dialysis efforts on the Northern Cheyenne Reservation

Prior to 1980, there were no organized efforts in the treatment and prevention of diabetes and dialysis on the reservation. Efforts up until that point in time were through individual patient/physician contacts and treatment. Statistical data and educational efforts were sketchy and often non-existant. In 1980, efforts towards documentation of the revalence and incidence of diabetes showed ninety patients diagnosed and one patients receiving treatment for dialysis.

During this time, the dialysis patients were transported to Billings three times a week for treatment at Deaconess Hospital. This process required a transfer driver to start picking up patients in Birney and Lame Deer at 4:00 a.m. The patients were treated and returned home approximately 14 hours later. Each patient needed to go through this rigorous schedule three times a week.

A. Northern Cheyenne Dialysis Program

In 1984, the Northern Cheyenne Tribe, under the direction of the Northern Cheyenne Board of Health, founded a Home Dialysis Program housed in Lame Deer. Local people, who speak the language were trained for six weeks at the

Deaconess Hospital in Billings. Dialysis for three patients was begun on January 9,1984. During that first year three more patients were treated, two died due to complications from diabetes. Currently, four people are receiving dialysis treatment and three more are being prepared to receive treatment. Based on 1985 laboratory data, twenty-six diabetics have nephropathy and possible candidates for dialysis in the near future.

The Northern Cheyenne Tribe is the primary funding source and future resources for the tribe look very bleak. This program may not continue in its present location. Transporting to Deaconess Hospital for treatment may be the only alternative, which would require scheduling of daily trips six days a week. Major obsticles that would need to be overcome include longer periods of time for patients to receive their treatment, vehicles equipped with oxygen and professional medically trained driver responsible for transporting, administering care to as many as six patients at once and be on duty sixteen hours a day, six days a week.

3. Current Indian Health Service efforts

Approximately 30% of all the Northern Cheyenne people over 40 years of age have diabetes. As of April 1986, there are 135 diagnosed diabetics who are active in our diabetes treatment program. 52% of these diabetics have been diagnosed in the past 5 years. The average age of these persons is 55.7 years.

A review of the presence of complications of diabetes among these people reveals that 44% have at least one complication (21% have retinopathy or eye damage, 24% have nephropathy or nerve damage, 16% have foot lesions, ulcerations, amputations).

A diabetic clinic and breakfast has been offered to those patients diagnosed as having diabetes. Services provided during this once a month program include: analysis of blood sugar, blood pressure, urine, foot care, education, nutritional assessment and counseling. Some patients are seen individually by one of the physicians by appointments on Tuesdays if there seems to be a problem with their treatment.

C. Diabetes Project

A proposal for assessing and changing services was submitted and funded in January, 1985. An advisory committee was set up to approach this problem from an interdisciplinary approach. Glucose monitors, exercise equipment, foot care, eye examinations, and bilingual educational materials were all added to the program. The primary focus of this project centers around patients that have been diagnosed as diabetic. The present program as it stands, is large [illegible]

Much of the work on the new project has been done by a volunteer. The ideas and beginnings that have been made could lead to a solid program with proper staffing and resources.

Of special interest is gestational diabetics; there were eight known cases of pregnancy induced diabetes in the past two years on the Northern Cheyenne Reservation. We are currently conducting a study to determine the incidence of the problems and are testing pregnant women.

III. Prevention of Diabetes Mellitus

Prevention of diabetes mellitus includes altering the susceptibility for the Northern Cheyenne people. This can be done thru education, active involvement in the health care system and finally behavioral changes by altering individual and group lifestyles taking into consideration major cultural aspects of the Northern Cheyenne people.

A. Primary prevention consists of general health promotion including provisions of conditions at home, work and school which favor healthy living, e.g. good nutrition, adequate clothing, shelter, rest and recreation.

For primary prevention we recommend the following. . .

School health curriculum developed to include a large section on alcohol education, nutritional aspects of all diseases and the causes and effects of diabetes.

Community knowledge expanded to include facts concerning the disease, to dispel some of the more rampant myths and misconceptions like being infectious and uncontrollable.

Work towards acceptance by community and religious leaders, the use of modern medicines and technology, along with changes in lifestyle that can indeed control the disease.

Research to find the primary causes of diabetes and possibly an epidemiological study of the Northern Cheyenne environment and cultural impact and implications of diabetes.

Family members can become involved by preventing diabetes by teaching weight control and exercise.

The use of an interdisciplinary approach to the education of Tribal leaders, health care professionals, para-professionals and health instructors in the schools.

3. Secondary prevention can be accomplished thru early detection and prompt treatment of diabetes. It is sometimes possible to slow the progression.

Diabetes risk is high blood pressure, overweight, hypoglycemia, [illegible] and fatigue. Have this screening available to all community members.

Screening of family members on a regular basis to determine whether early signs exist.

Work with and support family members to teach facts about diabetes and lifestyle changes including food selection and preparation, menu planning, amounts of activities (exercise) and maintaining ideal body weight.

Commitment to changing diet and exercise regime by individuals diagnosed with diabetes. Signs and symptoms are intangible and often ignored because they can't be seen or felt in a direct manner.

Resources available for individuals going through the mental anguish of first response to disease (i.e., denial, anger, blaming, & acceptance).

C. Tertiary prevention (appropriate in the stage of advanced disease or disability) is the alleviation of disability resulting from diabetes and attempts to restore effective functioning. Quality of life and closeness of support groups (i.e., family members, extended family members, religious groups and activities, rehabilitative facilities, health care facilities, translators, etc.) are vital to the Northern Cheyenne people.

For the Tertiary prevention are recommendations . . .

Continue with the Home Dialysis program at Lame Deer so that life can be as normally productive and functional as possible.

Continue with Diabetic program previously explained.

Make accessible statewide resources for individuals physically affected by diabetes (i.e. mechanical devices provided, home care, rehabilitation reading materials and tapes and rehabilitative activities).

D. Cultural aspects and ways of the Cheyenne people in dealing with the disease itself is an important factor to be taken into consideration. Diabetes is new to the culture, therefore, a pattern of dealing with this disease has not yet been established. It will take time to aculturate and process the needed knowledge and attitudes to confront and control this disease.

PREPARED STATEMENT OF ARTA CARLOW

I am Arta Carlow, Oglala Sioux member by birth, elected Tribal Health Representative from my home district. I have been elected by my peers as Chairperson for the Oglala Sioux Tribal Health Authority. The following is my testimony about adult onset diabetes. This testimony is given in support of the Native American Diabetes Prevention and Control Act:

1. # of Diabetics
2. # of male-female
3. # of amputations
4. # of kidney related incidences
5. # of vision problems
6. # of hypertensives
7. Water development

1. Number of Diabetics: The need for a diabetic study exists on this reservation. There is an inaccurate census of diabetics because we lack the personnel to do an in-depth screening process wherein we would be able to identify (1.) the diabetic and (2.) the borderline diabetic. This identity would enable our professional and paraprofessionals to work with them and help to prevent the diabetes progression through nutrition and weight control.

2. Number of male-female diabetics: The phenomena of diabetes, prevalent as equally among men as it is in the female. We need to know or identify why men are numerically equivalent in becoming diabetics as women. There are pregnant women experiencing diabetic pregnancy and after having their child, return to normal and often remain non-diabetic for years before becoming a mellitus diabetic. Since through pregnancy, women tend to be more diabetes prone, why are the men in our society equally subjected toward diabetes?

3. Amputations: The need to have accurate statistics of all diabetics is important to the development of prevention and treatment programs. We have a target population of diabetics that have not had contact with the various health programs designed for them. We need to be able to work with specific persons who are susceptible for an amputation to provide some form of prevention or treatment.

4. Kidney related incidences: Because of the escalated number of diabetics in the Indian societies, we are experiencing an increased number of kidey dialysis (nemodialysis) patients who depend on the dialysis as a life or death program. Once on the dialysis, the grim reality of kidney function loss gradually sets in and for some, periods of mental anxiety, depression occur. These residual effects need to be addressed by trained mental health personnel.

5. Vision problems caused by acute diabetes is also a prevalent problem in the Indian diabetic society. The on-going constant need for checkup and treatment exists which can be brought about through the establishment of the national "Native American Diabetes Prevention and Control Act".

6. Hypertension seems to be an illness contributed by diabetes and nutrition. Hypertension can be controlled with adequate nutrition and control of diabetes. Medication taken by hypertensives is available through the various Indian Health Service Pharmacies however, an increased need for counseling for the patient is needed. This can be corrected or improved by Health Education programs.

7. Water Development. The need for personal hygience exists in all societies. The water supply and systems on the reservations are not as readily available to the Indian residents. Many of the diabetics are of the older generation. Many living in homes 30-50 years old, have never had in-door plumbing and are expected by the health professionals to do exactly as instructed for foot care, personal hygiene. This is extremely difficult when one has to haul water from a creek 1/4 of a mile away or travel many miles to bring water home in a 5-10 gallon cream can, bucket, etc.

This is my testimony for my people on the Pine Ridge Reservation in support of the "Native American Diabetes Prevention Act".

PREPARED STATEMENT OF DON LAPOINTE

I am Donald LaPointe, a board member and member of the executive committee of the National Indian Health Board. I am also Vice-Chairman of the Keewenaw Bay Tribal Council in Baraga, Michigan. I am also Chief Executive Officer of the tribe. The National Indian Health Board is a private, non-profit corporation whose board of directors is comprised of tribal representatives elected by area Indian health boards or intertribal organizations in each of the twelve Indian Health Service geographically-defined service regions. The twelve elected representatives on the National Indian Health Board speak to the health issues affecting their constituencies which include 232 federally-recognized tribes, bands, and groups; 12 regional corporations and 202 Alaska Native villages within the State of Alaska; as well as 12 area health boards or intertribal councils and groups including several urban Indian health boards.

The National Indian Health Board is deeply concerned about the current health trends and policies of the federal government involvement in provision of health services to American Indians and Alaska Natives. The problem of diabetes mellitus is increasing each year. Senate bill S. 1988 begins to specifically address this health problem. We do appreciate the introduction of this bill and I should like to provide the Committee with our remarks concerning it.

In discussing the problem of diabetes with leading researchers across the country, we find that it is not a straight medical disease, rather, it is a disease caused by lifestyle. Additionally, we find that American Indians and Alaska Natives have a genetic tendency prone to diabetes and when they are overweight, the disease tends to be more prevalent. People get so heavy that their bodies become out of balance. We also find that nobody has a formula nor has anyone developed a pill to cure this disease. The cure is going to require a very strong preventive program as identified in S. 1988.

The funding for preventive medicine within the IHS has not been sufficiently addressed in past years. The shortage of funds has not allowed the model diabetes clinics currently in existence to expand into other clinical settings. S. 1988 also addresses this issue. Proper funding must be assured in order to expand this service.

We would recommend that the bill include provisions for a very strong nutrition program as well as a much stronger health education program to enlighten tribal members about this disease. The goal of S. 1988 is to achieve a reduction in the incidence of diabetes among Native American populations to a rate comparable to that of the general U.S. population. This is most admirable but, this same type of goal has been the mission of Indian Health Service for all health problems of American Indians and Alaska Natives since its transfer from the Bureau of Indian Affairs in 1955. The Indian Health Service is still so underfunded that the present budget only addresses about 40 per cent of the total identified unmet tribal health needs. Therefore, passage of the bill and enactment of the law alone does not achieve these goals. We also need to assure that necessary funds are provided to the Indian Health Service which would allow it to perform its obligations. The services provided by the IHS need to reach the people at the grass roots level and those services need to be identified in the bill as available for contract by the tribes under P.L. 93-638, the Indian Self-Determination and Education Assistance Act.

Additionally, the National Indian Health Board is concerned about the inclusion of Native Hawaiians in the services to be provided by the Indian Health Service. We recognize that the Native Hawaiian population also has genetic tendencies toward diabetes and should be provided some federal services, but those services should be provided through agencies other than IHS. We are fearful that any expansion of the IHS service population will further deplete the ability of IHS to meet its congressional mandate to American Indians and Alaska Natives. Therefore, if the Hawaiians should be retained in the bill we highly recommend that the Congress provide special funding to meet their needs and not extract any funds from the Indian Health Service for American Indians and Alaska Natives.

Kidney disease caused by diabetes is rapidly on the increase. The number of patients receiving dialysis exemplifies this reality. For example, the dialysis center in Tucson, Arizona currently has 22 Indian patients receiving dialysis. The cost of this service is most extensive and makes many financial demands not only upon the IHS, but also upon the tribes and the individuals themselves.

Blindness and amputations are also on the increase. Disabilities of these types can be controlled through a strong health education and prevention program, one that truly reaches the people. The program must coincide with the local environment and take into account cultural differences. The program must recognize that the difference in traditional foods and so-called "modern" foods is vast.

A tremendous behavioral change in eating habits is required and as each person serving in Congress knows, habits are most difficult to change. Additionally, since genetics are involved with the Native American when it comes to diabetes this becomes even more of a problem. There has not been sufficient research to determine how genetics are involved with this problem and we do recommend that S. 1988 provide for the necessary research to make this determination.

Finally, the National Indian Health Board has been informed that the Administration opposes S. 1988 and that the Indian Health Service must provide testimony opposing its enactment. We understand that the Administration will claim that it is already meeting this need. We disagree with any statement that may be provided by IHS that it is meeting the needs of American Indians and Alaska Natives when it comes to providing either prevention or treatment for diabetes. They do not have the money to meet the growing need. Not when experience has shown that they are only meeting some 40 per cent of the total identified unmet health need. Any type of piecemeal approach is not sufficient to meet any need, particularly when the difference is expressed in life and death figures.

We applaud the Committee for conducting hearings on this problem and we most certainly urge enactment of this bill, however, we do urgently request that the Committee give our comments their utmost consideration.

Thank you for allowing the National Indian Health Board this time to present our testimony. We did not go into all the statistics concerning this disease because Indian Health Service already has them available. We wanted to present this viewpoint from a grass roots perspective. If you have any questions, I shall be happy to respond. Thank you.

PREPARED STATEMENT OF DR. EVERETT R. RHOADES

Mr. Chairman and Members of the Committee:

I am Dr. Everett Rhoades, Director of the Indian Health Service (IHS). With me are Dr. Dorothy Gohdes, Director of the IHS Headquarters Diabetes Program, Mr. Bruce Leonard, Public Health Educator in IHS, and Dr. Peter Bennett, Chief, Phoenix Epidemiology and Clinical Research Branch NIH. We are pleased to be here today to discuss S.1988, the "Native American Diabetes Prevention and Control Act of 1985". The bill deals with the very serious problem of diabetes in the Indian community - the incidence of which has been increasing in recent years. Though diabetes can be treated and usually controlled it is an insidious condition with serious potential consequences including blindness, vascular obstruction and kidney failure.

We believe that the authorities contained in S. 1988 are not needed to continue or improve IHS diabetes programs. Furthermore, the bill could potentially narrow the focus of Federal efforts to improve the health status of Indians by drawing limited funds from other priority projects. For these reasons we do not support S.1988. I would like to make some general comments about diabetes, its impact on the Indian community, and what the IHS is currently doing about it.

Non-insulin-dependent diabetes (NIDDM) or Type II Diabetes is a major health problem in American Indian communities. Since 1940, the incidence of diabetes has increased dramatically in many tribes. Current theories suggest that American Indians and certain other populations carry a "thrifty gene" which was advantageous during periods of alternating feast and famine. With sedentary lifestyles and high fat food sources, people with the "thrifty gene"

are prone to obesity and Type II Diabetes. Precise data are available for the Pima Indians because of a continuing longitudial study of diabetes conducted by the National Institutes of Health.

In recent years the complications of diabetes have become more frequent as the number of patients with longstanding diabetes has increased. In Fiscal Year (FY) 1983, 76% of lower extremity amputations done by IHS or under contract were performed on patients with diabetes. The comparable figure for lower extremity amputations in the overall United States population is 50%.

Data on diabetes and end-stage renal disease (ESRD) in American Indians reveal a growing problem. In the states of Arizona and New Mexico, the renal failure rate for American Indians is 3.5 times the rate for whites. 50% of the Indian ESRD patients have diabetes. Figures for the U.S. population show that 25% of ESRD is diabetes related. Exact figures for blindness related to diabetes are not available, but the Gallup Indian Medical Center treated 24 patients with proliferative diabetic retinopathy in the first quarter of FY 1986. In the Pima study, 46.8% of patients with diabetes for 10 or more years had some form of retinopathy. Of the direct IHS and contract discharges in FY 1983 for ischemic heart disease, 29% also had diabetes listed as a discharge diagnosis. The rate for first cataract surgery was 2.2 times higher in Pima diabetic patients than non-diabetic Pimas.

Periodontal disease associated with diabetes is now being described among Indians. Loss of teeth for those over 75 occurred in 33% of diabetic Pimas but only 2% of non-diabetics. Perinatal mortality from the 1970's for pregnant diabetic Pimas was 25.5% compared to 1.2% for normal pregnancies.

The rate of congenital anomalies was 3.8% in normal and prediabetic pregnancies compared to 19% in diabetic pregnancies. Experience among thePimas suggest that careful metabolic control of diabetic women during pregnancy improves perinatal mortality markedly.

Standard morbidity and mortality measurement confirm that the diabetes problems of the Pima are generally applicable to the overall Indian population. The age-adjusted diabetes death rate (per 100,000 population) for U.S. all races in 1982 was 9.6 when the comparable rate for American Indians residing in IHS service areas was 25.5 (1981-83). The age-adjusted rate of annual hospital days per 10,000 population for the IHS service area was 315.6 (1982-83) compared to 275.0 (1983) for the U.S. The age-adjusted discharge rate per 10,000 population for the IHS service area was 39.8 (1982-84) compared to 29.1 (1983) for the United States.

The number of outpatient visits for diabetes has been steadily rising for 15 years. In FY 1981, 25,970 patients visited IHS facilities for diabetes. By 1984, 30,729 were seen. Among the Pima Indians the prevalence of diabetes increased 42% between 1967 and 1977. These trends are expected to continue. Morbidity and mortality will probably grow despite all our efforts, because the numbers of patients with longstanding poorly controlled diabetes will rise. The incidence of diabetes has increased by 1/3 among the Pimas comparing 1965-74 with 1975-84. We are concerned that other Indian communities will see comparable increases.

The IHS has in place a significant diabetes prevention and treatment program. It began in 1979 with the development of 5 model care sites. Since then, the

program has developed along several lines. Additional model sites have been added and several types of outreach activities have been initiated to improve the care and prevention of diabetes throughout IHS.

The original five model projects were developed in different types of facilities in different settings so that experience gained in the sites could be applied in a wide variety of service units. Most teams consist of nursing, nutrition, and physician assistants. Several sites have physicians. The teams work as an integral part of the service unit. A brief description of each follows:

(1) The Ft. Totten Service Unit serves about 3330 patients on the Devil's Lake Sioux Reservation in North Dakota. The diabetes team visits homes and works in a small clinic. A consultant endocrinologist from the University of North Dakota holds clinics periodically. Currently there are 165 patients including 5 amputees, 1 dialysis patient, 2 with end stage renal disease (ERSD) not receiving dialysis, and 4 have had laser therapy. 32% of the diabetic patients are hypertensive. In FY 1984 they saw 15 new patients and 17 in FY 1985.

(2) The Winnebago-Omaha, Nebraska Diabetes staff works with the Omaha Tribal Clinic and the Winnebago Hospital and Health Department. Within a population of 4,593 there are 430 patients with diabetes including 23 amputees, 19 dialysis patients, and 27 who have received laser treatment. 32% of the diabetic patients are hypertensive. There were 41 new patients in 1984 and 43 in 1985. The team has developed an approach to diet counseling tailored to this community. The materials to support this approach are now in draft for wide distribution in IHS.

(3) The Claremore team follows 1,000-1,200 active patients in eastern Oklahoma from a multiservice medical center. There is not a distinct reservation but the service population is about 63,000. In 1984 the team saw 130 new patients. This increased to 169 in 1985. A day care program providesintensive education. Followup is carried out in high flow clinics. This team assists other clinics in establishing and evaluating diabetes care.

(4) The Albuquerque team follows 660 patients with diabetes from a service population of 17,813. These patients live in Pueblo villages, the Alamo Navajo Reservation, and the urban environment of Albuquerque. There are 7 amputees, and 13 who have had laser treatment. There are 4 dialysis patients from the villages. 32% of the diabetic patients are hypertensive. In 1984 there were 92 new patients to the program. There were 86 new patients in 1985.

(5) Sacaton Service Unit is the site of the ongoing National Institutes of Health (NIH) study of diabetes. As of September 1985, it has been reported that half the adults over 35 are known to have diabetes. The diabetes team has a current census of 359 and has had contact with 311 more. There were 65 new patients in 1984 and 86 in 1985. Out of a total population of about 10,000, our latest figures indicate there are 48 patients on dialysis.

Two additional projects were begun in the summer of 1985. In Washington State, the Lummi Service Unit is developing a program with computer based flow sheets for following diabetic patients. Cooperative efforts with other Portland Area service units are an integral part of the initial planning. In Maine, the tribes are developing a strong preventive/screening program under tribal auspices.

As the Diabetes Program developed, many health care providers approached staff with questions about Type II Diabetes and Indians. There were widespread misunderstandings about complications. The staff became involved in training and technical assistance. A two day course on Diabetes in Indians wasdeveloped using faculty from major universities and the IHS program. In FY 1985 there were 6 cooperative workshops for health care professionals involving 500 people from 16 states. Community Health Representative training was initiated. In FY 1985 staff were involved in 42 site visits in 13 states. The Winnebago Service Unit has a training rotation for nurses and dietitians. IHS diabetes training has incorporated materials or faculty from the American Diabetes Association (ADA), the National Diabetes Advisory Board (NDAB), and the University of Michigan Diabetes Research and Training Center (DRTC).

In FY 1984 and FY 1985 Service Units submitted proposals for seed monies to improve diabetes care at their service unit. These were reviewed by a technical panel and ranked. Money was distributed to the top ranking proposals. Attached is a listing of these projects.

Several Areas have now designated diabetes control officers. Diabetes control officers collect surveillance data about diabetes and supervise audits of care practices. Educational materials and standards of care are disseminated to all service units promptly. Orientation and ongoing training in diabetes is coordinated by the diabetes control officers.

The Headquarters Diabetes Program provides technical supervision for the model sites, coordinates training, and has identified barriers to care in IHS. The Headquarters program works with the NDAB, National Diabetes Information Clearing house (NDIC), DRTC, Center for Disease Control (CDC). Picture diet manuals for Southwestern and Plains Indians foods are now available. A CHR training package is under development along with other diabetes educational materials.

In summary, we believe that the IHS is already directing its efforts toward the goals of S.1988. Model sites develop comprehensive approaches to preventive health services in "typical" settings. The expertise in diabetes is shared through training programs and on site technical assistance. Seed monies allow other service units to improve their diabetes services. Indian oriented materials are developed and disseminated through diabetes control officers. Current information about the extent of diabetes and its complications is collected by diabetes control officers. Indian communities can obtain information and technical assistance from the program as needed. The authorities contained in S.1988 are redundant or unnecessary or would in some instances direct limited resources from higher priority activities.

This concludes my prepared statement. We will be happy to answer any questions you may have.

ONE-TIME INITIATIVE FUNDING - FY 86

All proposals will determine the incidence and prevalence of diabetes in a funded group. Those funded will design, develop and operate a diabetes screening clinic and produce a detailed final report of their conclusions.

PROPOSALS AWARDED

800	Red Lake, Minnesota	$4,000.00
662	Cass Lake, Minnesota	$7,486.00
600	Tahlequah, Oklahoma	$7,327.40
562	White Earth, Minnesota	$7,500.00
550	Oneida, Wisconsin	$4,770.00
528	Sanders, Arizona	$1,350.00
485	Seattle, Washington	$7,500.00
471	Shiprock, New Mexico	$7,450.00
471	Crownpoint, New Mexico	$7,498.00
450	Tollhouse, California	$7,133.00
442	Hogansburg, New York	$7,490.00
387	Pine Ridge, South Dakota	$4,491.00
357	Atmore, Alabama	$7,500.00
342	Trenton, North Dakota	$2,200.00

ONE - TIME AWARDS
FY 84

FT. BERTHOLD, NORTH DAKOTA..... $14,220.00

This project established jogging trails, screened for diabetes at health fairs, developed an educational program in community schools and provided resources for aerobics instruction.

BELCOURT, NORTH DAKOTA..... $ 5,170.00

Normalize glucose control in a selected group of 20 diabetic patients through diet, activity and medication, using home glucose monitoring. Intensive nutritional teaching was provided to produce weight loss and ideal control.

WHITE EARTH, MINNESOTA..... $14,442.00

A general diabetic education component was provided using films, tapes and slides. A model meal program utilizing selection and preparation of foods was provided. 10% of the diabetic population was provided with glucose monitoring supplies to enhance awareness of food, exercise, and medication balance.

FORT YUMA, CALIFORNIA..... $ 9,607.50

Hands on classes in meal planning and food preparation were designed and presented. Key personnel left and project was ended.

CARL ALBERT, OKLAHOMA..... $20,575.00

This project utilized a non-invasive method to obtain information on diabetic vascular disease (lower extremity arterial measurement). Screening identification and referral of patients for revascularization surgery.

PORTLAND AREA..... $ 7,575.00

This project was funded to develop script and slides for a teaching series tailored for local people to illustrate desired behavior in diabetes management. This project was not successfully completed.

ROSEBUD, SOUTH DAKOTA..... $14,220.00

This project produced a home glucose monitoring program on the reservation to improve diabetes control (particularly in the pregnant patient). The project also successfully produced a number of diabetic education video tapes.

SAN CARLOS, ARIZONA..... $14,722.00

This project built a walking/jogging trail to promote "pathway to health" for diabetic patients. A home glucose monitoring program was designed and implemented for gestational diabetic patients to strive for tight control through better self-management. Successful program.

ONE - TIME AWARDS
FY 85

NARRANGANSETT INDIAN TRIBE, RHODE ISLAND..... $10,892.00

The development of a video tape on health promotion in diabetes. Design and assembly of a diabetic educational kit. To train the medical staff in the use of the educational kit, blood glucose monitoring and diabetic prevention advertising program.

TUBA CITY (HOPI), ARIZONA..... $12,929.00

Development of Hope specific diabetes teaching materials and activities. Community awareness program on diabetes.

PIERRE SOUTH DAKOTA SERVICE UNIT, SOUTH DAKOTA..... $ 9,000.00

The development and coordination of multidisciplinary Diabetes Team.

LEECH LAKE RESERVATION, MINNESOTA..... $ 5,300.00

Development of diabetes support groups and educational programs. The implementation of a referral system between health descriptions.

WESTERN OREGON..... $ 4,460.00

Diabetes risk reduction for students through weight reduction and nutritional counseling.

BOSTON INDIAN COUNCIL, MASSACHUSETTS..... $ 1,275.00

Case detection through screening and GTT testing. Diabetes education including nutrition and family counseling.

ROCKY BAY HEALTH BOARD, MONTANA..... $15,000.00

Design and implement a physical fitness program to lower risk factors of diabetes. Nutritional analysis with weight control.

NORTHERN CHEYENNE, MONTANA..... $15,110.00

Re-design of the diabetes management system including clinical and education.

CROW AGENCY, MONTANTA..... $15,000.00

Diabetes retreat for newly diagnosed patients, glucose monitoring and patient education materials.

WARM SPRINGS, OREGON..... $ 1,900.00

Aerobic exercise program for diabetics including effect on blood sugar control.

PREPARED STATEMENT OF DR. PETER H. BENNETT

Mr. Chairman and Members of the Committee:

I am Dr. Peter H. Bennett, Chief of the Phoenix Epidemiology and Clinical Research Branch of the National Institute of Diabetes and Digestive and Kidney Diseases. I am very pleased to have the opportunity to testify before you today about our research efforts to investigate the occurrence and causes of diabetes mellitus and its complications in Native Americans.

The National Institute of Diabetes and Digestive and Kidney Diseases initiated an investigation of diabetes mellitus among American Indians in 1965. The first investigation, conducted among the Pima Indian population of the Gila River Indian Reservation in Arizona, showed that diabetes among the Pima was 10-15 times as frequent as in the general United States population and that, among those with diabetes, the characteristic vascular complications of the disease, such as diabetic retinopathy and diabetic nephropathy (kidney disease due to diabetes) occurred with frequencies similar to those reported in diabetics of different ethnic groups elsewhere.

This extraordinary finding led to an immediate decision by the Institute to establish a longitudinal study of this population in order to: 1) determine the reasons for the unusually high frequency; 2) define the determinants, or causes, of the diabetes in the population; 3) investigate the development, or natural history; and 4) determine the causes and natural history of the specific complications.

An in-depth knowledge of the determinants and pathogenesis of the disease and its complications are prerequisites to the design and institution of scientifically based methods of treatment and prevention. The continuing study of diabetes, particularly among the Gila River Indian Community, contributes in a major way to the mission of the Phoenix Epidemiology and Clinical Research Branch of the Institute. That mission is to conduct direct and collaborative field studies to investigate the epidemiologic, genetic, and environmental determinants of diabetes in selected American Indian populations; to conduct clinical and laboratory research in the disease processes of diabetes and other diseases, with particular emphasis on those more prevalent among the American Indian population, and to expedite the application of research results in the Indian Health Service programs through improved understanding of the causes, treatment, and prevention of these diseases.

The interest of the Institute and an expanding commitment to this program through the years have resulted in the most extensive and largest prospective study of diabetes mellitus that has been performed anywhere in the world.

I would now like to describe some of our findings and discuss the current and anticipated future directions of this research effort.

Occurrence of Diabetes in American Indians

Diabetes among American Indians and Native Hawaiians is almost exclusively of the non-insulin dependent type. This type of diabetes accounts for

80-90 percent of all diabetes in the United States and an even higher percentage worldwide. It usually attacks those aged 40 years and over in contrast to insulin dependent diabetes, which more often affects Caucasian children and adolescents. Nevertheless, both types are associated with a similar spectrum of complications, although the underlying pathogenesis is quite different.

Among American Indians, diabetes was reported to be rare before 1940, and indeed, up until the early sixties, Alaskan Eskimos and Aleuts appeared to have less non-insulin dependent diabetes than other Americans. However, the disease appears to have become much more frequent in recent years among all American Indian tribes. In the Pima, for example, there was a 40 percent increase in the age-adjusted prevalence of the disease between 1967 and 1977, and the incidence (that is, the rate of development in new cases) increased to a similar degree during periods centered around 1970 and 1980. Among the Alaskan Eskimos and Aleuts, the disease is no longer believed to be rare. Little is known about the prevalence in native Hawaiians, except that in 1963 the disease was reported to be more common than in any other ethnic group in Hawaii; that impression apparently remains today. Certainly, other people of Polynesian origin, such as the Maori in New Zealand, have significantly higher prevalences of diabetes than Caucasians living in the same country.

Among American Indians, the prevalence of diabetes varies appreciably from tribe to tribe. Our studies in the southwest United States have indicated that the Papago have a prevalence approaching that of the Pima, whereas some other tribes, such as the San Carlos Apache Indians and the Cocopah, have

somewhat lower frequencies, but still rates much higher than in the Caucasian population. A comparison of the rates of development of new cases of the disease in the Pima Indians with those of the predominantly Caucasian population of Rochester, Minnesota, indicates that diabetes develops twenty times as frequently among the Pima.

Complications of Diabetes in the American Indian

Most of the morbidity and mortality associated with non-insulin dependent diabetes arise from the vascular complications associated with the disease. These complications include diabetic retinopathy, which frequently leads to blindness; diabetic nephropathy, one of the more serious and previously fatal conditions, which leads to end-stage renal disease; and increased frequency of atherosclerosis, which leads to excessive frequencies of coronary heart disease and lower-limb vascular disease. The latter is associated with very much higher rates of gangrene and amputation that result in serious incapacity and disability.

Our efforts have included investigating the reasons for the development of these vascular complications in non-insulin dependent diabetes. For example, we know that the duration of the disease plays an important role in the development of nephropathy, retinopathy, and atherosclerotic disease. Also, the degree of hyperglycemia and blood pressure level are related to the rate of development of each of these complications. While hypertension was once believed to be a complication of the diabetes, our data and those of other

investigators now indicate that in fact hypertension causes several types of vascular disease in the diabetic.

Diabetic nephropathy is one complication that is relatively more significant among American Indian diabetics than others, probably because of the earlier age at which the diabetes usually develops in the American Indian. A recent follow-up study has shown nephropathy was the underlying cause of death in 40 percent of the Pima Indians with diabetes followed over an eight-year period. Our longitudinal study also has shown that in those with diabetes of more than 20 years duration, over 30 percent have developed renal insufficiency. This condition, which was formerly uniformly fatal, necessitates treatment by renal dialysis or renal transplantation for the continuation of life, imposing large demands on health services and a tremendous burden on the unfortunate patients who must endure such treatments. Among the Pima Indian population, dialysis, at the present time, is about 15 times as frequent as in the general U.S. population, in spite of the Pima population being appreciably younger. With the increasing frequency of diabetes during the past 20 years, we anticipate that the numbers of Pima Indians requiring such treatment will inevitably increase considerably in the forthcoming years, unless some radical new approach to the management of diabetic renal disease can be found. Because of the significance of this complication to the American Indian community, and the potential for research advances in renal disease caused by diabetes, our Institute is currently soliciting contract proposals to investigate the determinants of diabetic nephropathy in the Pima Indian population and to conduct controlled clinical trials of interventions that instead may potentially delay or stop the progression of this complication.

Diabetes and Pregnancy

The outcome of pregnancy is also influenced by non-insulin dependent diabetes. Our studies among the Pima Indians have shown that the offspring of diabetic pregnancies suffer excessively high rates of morbidity in the newborn period and experience long-term sequelae such as extreme obesity and much higher rates of diabetes as adolescents and young adults. While perinatal mortality remains higher in the offspring of the diabetic pregnancy, the rate has fallen considerably in recent years, presumably as a result of improved medical care and management. The offspring, however, continue to be large for gestational age at birth. They also have a four- to fivefold increased rate of congenital anomalies, or birth defects, which arise as a result of the abnormal metabolism in the intrauterine environment during the first trimester of pregnancy. By the age of 15-19 years, about 40 percent already have diabetes themselves, as compared to about 3 percent of similar aged offspring whose mothers were not diabetic at the time of pregnancy. Whether or not these long-term complications of the diabetic pregnancy that were first recognized and documented among the Pima Indian population can be prevented by better control and management of diabetes during pregnancy remains to be determined.

Causes and Pathogenesis of Diabetes in the American Indian

The most important research goal of our Institute in the ongoing investigations of diabetes among the Pima Indians is to identify the

determinants and pathogenesis of the diabetes itself. Such knowledge is necessary if there is to be any likelihood of preventing the disease.

Genetic factors are important and are probably a prerequisite in determining the susceptibility of the individual to developing non-insulin dependent diabetes. Environmental factors also play a critical role in determining whether or not the disease develops in susceptible individuals. The increasing frequency of the disease over a ten- or twenty-year period and the effects of diabetic pregnancy on diabetes in the offspring can only be attributed to the effect of precipitating factors in the environment.

The precise nature and role of environmental factors as precipitants of the disease, however, are only partially defined at this time. Obesity is an important factor that interacts with the genetic susceptibility to determine whether or not diabetes develops and the age at which it does so. The causation of obesity, however, is as elusive in the American Indian as it is in other ethnic groups. An excessive intake of calories relative to caloric expenditure is a prerequisite for the development of obesity. It is unknown whether or not this excess arises as a result of an increase in caloric intake or a decrease in caloric expenditure, resulting from reduced physical activity or possibly from a metabolic abnormality that leads to lower-than-usual caloric requirements for daily living. The Institute's Clinical Research Section in the Phoenix Indian Medical Center is undertaking a series of studies designed specifically to address these questions. Indeed, the level of sophistication of these studies is probably greater than anywhere else in the United States at this time.

The epidemiologic and clinical research studies among the Pima are yielding a more in-depth knowledge of the pathogenesis of non-insulin dependent diabetes in the general population than ever before. Subjects with impaired glucose tolerance (but with glucose tolerance levels that are less than those diagnostic of diabetes) have a high risk of developing diabetes, although not all of them do so. This is true in the Pima Indians as in other populations.

Our earlier investigations showed that the non-diabetic Pima, in general, had higher insulin levels than Caucasians of similar age and obesity. Thus, we formulated the hypothesis that inadequate insulin action, or insulin resistance, was probably the underlying defect related to the likelihood of the American Indians to develop diabetes.

Further research, using new techniques to measure insulin resistance and to define the reasons for it, has now shown that insulin resistance is uniformly present in Pima Indians with non-insulin dependent diabetes, and that insulin resistance increases proportionally with the degree of glucose intolerance in non-diabetic subjects. Thus, those with impaired glucose tolerance have appreciably greater insulin resistance, on average, than those with normal glucose tolerance. Furthermore, our investigators have shown that insulin resistance is the result of inability of the body, and of muscle in particular, to store glucose in a normal manner. This abnormality appears to be due to a derangement in the intracellular pathway for the processing of glucose and the formation of glycogen. While insulin resistance is known to be affected by obesity and physical activity, our investigators now have demonstrated that this derangement shows familial aggregation. The identification of this defect may, therefore, be the essential clue in

defining the genetic factors which underlie the susceptibility to non-insulin dependent diabetes.

Individuals with impaired glucose tolerance and insulin levels that are above normal, but are lower than average for this group, are the subjects who are most likely to develop diabetes. These findings, therefore, suggest that if specific ways can be found to increase the intracellular glucose storage pathway and/or insulin secretion in those with impaired glucose tolerance, then the progression to diabetes may be preventable. Identification of the precise genetic mechanisms relating to insulin resistance could also lead to identification of those genetically susceptible at a time when their glucose tolerance is still entirely normal. If this were possible, then preventive measures could be instituted early in life and targeted specifically at individuals who would otherwise develop the disease.

Prospects for Prevention and Control

Impaired glucose tolerance indicates a high risk of diabetes, and such affected persons constitute a group in whom several possible intervention strategies to prevent or postpone the development of non-insulin dependent diabetes--possibly dietary measures and exercise--could be assessed. The effectiveness of such measures, however, has not yet been adequately demonstrated. Such preventive approaches--and eventually perhaps intervention at an earlier stage if genetically susceptible individuals can be identified--offer the best hope that the incidence of non-insulin dependent diabetes in the American Indians, and in other populations, can be reduced. In the

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meantime, efforts to minimize the effects of hyperglycemia in those with diabetes and efforts to provide effective treatment for diabetic nephropathy, diabetic retinopathy and other complications, as well as careful management and control of the diabetic pregnancy to minimize the effects on infant morbidity, are well established and provide the mainstay of conventional care for the disease.

I appreciate the opportunity to testify before you today concerning diabetes and its impact on the American Indian, and to inform you about our ongoing research activities in this area. I shall be pleased to answer any questions that you may have.

PREPARED STATEMENT OF EDWARD S. HORTON, M.D.

I am Edward S. Horton, Professor and Associate Chairman of Medicine, Department of Medicine, University of Vermont, and member of the National Diabetes Advisory Board. I appreciate the opportunity to appear before you to present the recommendations of the National Diabetes Advisory Board on S. 1988.

The National Diabetes Advisory Board was established by Congress in 1976 to review, evaluate, and report on national diabetes-related activities. In annual reports and in testimony berfore various committees of Congress, the Board has described the extent of diabetes and its complications among American Indian people and made recommendations to combat this rapidly growing problem.

Whether expressed in terms of prevalence, morbidity, premature mortality, or economic impact, diabetes among American Indians is significantly more severe than in other U.S. population groups. Diabetes occurred quite infrequently in American Indians 50 years ago, but the diagnosis of diabetes became progressively more common by the 1960's. Today, diabetes in some tribes has achieved epidemic proportions. A startling 50 percent of Pima Indians over the age of 35 have diabetes, and prevalence rates greater than 20 percent among adults have been reported in several tribes in Arizona, New Mexico, Nevada, Oklahoma, Florida, North Carolina, and New York.

The serious complications of diabetes are increasing in frequency among American Indians, especially renal failure, amputations, and blindness. The costs of managing diabetes and its complications also are increasing rapidly:

- The treatment for renal failure--kidney dialysis or transplantation--is particularly expensive. The annual cost of treating the current patient population of American Indians with chronic renal failure exceeds $10 million and is increasing rapidly.

- American Indians with diabetes account for approximately 75 percent of all amputations within the IHS health care system. The annual hospital-related costs alone of these amputations exceed $3 million, exclusive of the cost of rehabilitation or disability.

Cost effective prevention and treatment strategies are available to reduce the rate and severity of these and other complications of diabetes. Diabetes specialists familiar with the American Indian population have recommended implementing these strategies without delay to reduce the growing economic and social costs of this disease.

In recognition of the severity of the problem, the Indian Health Service developed a plan for a Model Diabetes Care Program to be established at several existing IHS service units. The Board supported this plan and recommended that additional funds be appropriated for this purpose. Congress subsequently approved funds to implement the program in fiscal year 1979. Five initial project sites were chosen to represent different types of IHS facilities and population groups. The Claremore (Oklahoma) Indian Hospital is a multiservice referral facility located off the reservation. The Fort Totten (North Dakota) Health Center is a reservation-based clinic. The Sacaton (Arizona) program

uses a small hospital with outlying clinics on the Pima reservation. The Winnebago (Nebraska) program uses both the reservation hospital and the tribally operated facility on the Omaha reservation. The Albuquerque (New Mexico) program serves both urban and rural indians. Two additional projects were initiated in 1985 in Maine and in the Pacific Northwest. The small headquarters staff of the Model Diabetes Care Program is located in Albuquerque.

Multidisciplinary teams have been established at each site to intensify preventive services and to develop a comprehensive diabetes care plan that includes routine screening for complications, patient education and nutrition counseling, and attention to related conditions such as hypertension, urinary tract infections, and foot care. Considerable progress has been made at these sites in delivering high-quality, culturally acceptable diabetes care.

The model sites serve only about 10 percent of the IHS population. Transfer of effective treatment strategies from the model sites to other service units has only begun. Requests for education, training, and assistance far exceed the available personnel and resources of the small core program staff. Although limited by financial restrictions, the program has begun modest but critical outreach activities. The Board believes that additional resources should be provided to accelerate this activity and reduce the rapidly growing rate of diabetes-related complications that threaten the future clinical and financial resources of IHS.

The current budget for the model diabetes program is $1.9 million. This small program must be expanded to address the growing health problem of diabetes. Additional personnel positions also are needed to implement the expanded program. The Board has already recommended that the budget for

this program be increased from $1.9 million to $2.9 million in fiscal year 1987.

The Board supports statutory authorization of an expanded program for the prevention and control of diabetes among Native Americans. The growing health and economic problem of this disease justifies a concerted effort to reduce the future incidence of diabetes and improve the treatment of its complications in this high risk population. The economic burden of diabetes is already straining the IHS budget. A comprehensive control program must be developed to prevent even larger Federal expenditures in the future. Fortunately, the accomplishments of the current Model Diabetes Care Program provide an excellent base for an expanded, cost effective, diabetes control initiative.

We have reviewed the specific provisions of S. 1988 and provide the following comments for the committee's consideration:

Section 3.

The nature and magnitude of the diabetes problem among Native Americans has changed rapidly in recent years. Therefore, the proposed study on diabetes among Native Americans is needed to determine the prevalence of the disease among various tribes and to assess its full impact upon the IHS health care system. The study will provide useful information for the development of intervention initiatives by the IHS and other interested organizations.

Section 4.

Subsection (a) (2) identifies the three specific challenges facing the Indian Health Service: to reduce the future incidence of diabetes in this high-risk population; to effectively treat newly diagnosed patients in order

to reduce future complications; and to effectively treat the present complications of diabetes already evident in this population. Standards for the prevention and treatment of diabetes in this high-risk population have been developed by diabetes specialists. These standards, including screening and detection programs and provision for patient education for self-care, must be implemented throughout the Indian Health Service.

Subsection (a) (3) gives priority to the training of all health care providers and community health representatives in current methods of prevention, diagnosis, and treatment of diabetes. In addition, our information indicates that approximately 20 percent of IHS physicians and registered nurses are new to IHS each year. Therefore, health care providers must be continuously oriented to the unique community/lifestyle factors that influence the development and treatment of noninsulin-dependent diabetes in this population.

We endorse the continuation of the present seven model diabetes clinics identified in subsection (c) (1) and support the establishment of additional model clinics, (c) (2). We recommend that at least one model clinic be established in each administrative area of the IHS to serve as a focal point for the implementation of effective treatment strategies in all service units. Therefore, model clinics should be established on the Navajo and Papago Reservations and in Montana and Minnesota, as proposed. Since the IHS does not operate clinics in Hawaii, other government agencies that provide health care services in that state could be assigned responsibility for development of a comparable model diabetes clinic, perhaps with technical assistance from IHS staff. We also recommend that a model clinic be established in Alaska.

Subsection (c) (3) identifies a major goal of this initiative, i.e., the ultimate transfer of effective treatment strategies to all IHS service units. The IHS should establish procedures to insure that all administrative areas, service units, and central offices implement the established standards of diabetes care that will facilitate progress toward this goal. This outreach initiative should include assistance to tribes for community program development and provide for coordination of community and health service unit activities.

Subsection (d) addresses the need to assign adequate numbers of appropriate personnel to this initiative. For example, a full-time diabetes control officer is required for each IHS administrative area to provide technical assistance, identify barriers to effective care, develop area plans, implement diabetes prevention and treatment standards, conduct training programs, evaluate area activities, develop community education programs, and collect and analyze data related to diabetes and its complications. Additional physicians, health educators, and other support personnel also are needed to strengthen the current model diabetes care programs and the Albuquerque headquarters staff.

Section 5.

A comprehensive, standardized data system within IHS is needed to assess trends and evaluate progress in diabetes control. This system must be capable of providing data related to the prevalence and incidence of diabetes and its complications in different geographic areas, including amputation rates, end-stage renal disease rates, rates of cardiovascular events, rates of visual impairment, rates of diabetes in pregnancy, and incidence of congenital anomalies. In addition, the data system must be capable of providing information about diabetes-related medical services required, including rates of hospitalization, use of laser therapy, and other services.

Section 6.

The Board supports the requirement to give special attention to research concerning the causes, diagnosis, treatment, and prevention of diabetes and its complications among Native Americans. The National Institute of Diabetes and Digestive and Kidney Diseases, the lead agency for diabetes research, supports a diabetes research program among the American Indian population in the Phoenix, Arizona, area. This program should be provided adequate support to pursue promising research opportunities.

In conclusion, the Board endorses S. 1988. Our support for the establishment of a comprehensive diabetes prevention and treatment program is consistent with the results of a diabetes survey conducted among all American Indian tribes for the last 6 months by a coalition of interested organizations. The survey results indicated, for example, that all of the respondents were aware of the seriousness of diabetes in their community; however, only 22 percent had developed materials to edueate their community about diabetes. Ninety-one percent of the respondents stated that they would welcome technical assistance in community control of diabetes. Fifty-four percent were aware of the IHS Model Diabetes Care Program and 33 percent had received some assistance or training from the program staff. The latter figure is commendable, given the small size of the current program's staff, but indicates the extent of the task yet to be addressed.

The Board supports an expanded initiative to reduce the impact of this disease among Native Americans and appreciates the opportunity to appear before this committee. We would be pleased to respond to any questions.

PREPARED STATEMENT OF NEAL FRIEDMAN, M.D.

Mr. Chairman,

My name is Neal Friedman. I am currently President of the New Mexico Affiliate of the American Diabetes Association and the Chairman of the Department of Endocrinology at Lovelace Medical Center in Albuquerque, New Mexico. I am also an Associate Clinical Professor of Medicine at the University of New Mexico. Between 1976 and 1978 I was with the Indian Health Service at Zuni Pueblo, New Mexico, where I participated in the development of the first diabetes clinic.

The American Diabetes Associates is a non-profit organization that has over 800 affiliates and chapters nationwide and more than 220,000 members, including lay persons, physicians, research scientists, nurses, dietitians, and educators. The purpose of the ADA is to promote research related to curing and preventing diabetes, and to improve the well-being of people with diabetes and their families.

Need For S.1988

The American Diabetes Association is pleased to be able to participate in this hearing on the Native American Diabetes Prevention and Control Act of 1985, S.1988. We have consistently supported existing programs that seek to address

the problem of diabetes within the Native American population, with particular emphasis on the Model Diabetes Care Program operated by the Indian Health Service and headquartered in Albuquerque New Mexico. Unfortunately, current efforts are clearly inadequate to meet the growing incidence and health impact of diabetes among American Indians. For this reason, we wholeheartedly recommend the enactment of Senate Bill 1988, which would substantially expand the present efforts of the Indian Health Service while proposing new initiatives designed to better the understanding and control of the widespread effects of diabetes among Native Americans.

The prevalence and impact of diabetes among Native Americans is significantly greater than among other population groups. In its January 1986 Report of the Secretary's Task Force on Black and Minority Health, the Department of Health and Human Services stated that:

> "the increase in diabetes among Native Americans can only be termed an epidemic. Native Americans are more than ten times as likely as whites to incur non-insulin dependent diabetes. One tribe, the Pima Indians, has the highest rate of diabetes in the world."

The serious complications of diabetes are widespread among American Indians, particularly kidney disease, amputation and blindness. These complications are major causes of hospitalization and morbidity in most Native American populations, and the associated social and economic costs are severe. For example, the number of Native Americans with

end-stage renal disease is growing rapidly. This debilitating complication of diabetes is ~~presently~~ treatable only through kidney dialysis or transplantation.

The American Diabetes Association is in full agreement with the conclusion of the Task Force that "Extensive innovative efforts are needed to interrupt the increasing prevalence of diabetes among North American Indians and reduce morbidity and mortality". Having agreed that this compelling need exists,, we are pleased to offer our comments on Senate Bill 1988.

Specific Comments on Senate Bill 1988

Although prior studies have demonstrated that non-insulin dependent diabetes (NIDDM) is especially prevalent among American Indians, there remains substantial uncertainty with regard to variations of incidence among different sectors within the North American Indian population. For this reason, section three of the bill requiring the Secretary of Health and Human Services to study and report on the incidence of diabetes among Native Americans is very important. We recommend that the study by the Secretary examine the variations in yearly incidence of diabetes among the various tribes and geographic regions. This information may assist in identifying those factors which are associated with extreme prevalence of diabetes.

Section 4(a) of the bill directs the Secretary to strengthen and expand the current activities of the diabetes control program of the Indian Health Service and to initiate new programs for training and health care delivery relating to the treatment of diabetes and related complications among Native Americans. Because the Indian Health Service is the chief health care provider for Native Americans, initiatives under section 4(a) would have a broad-based impact. One important area for emphasis under section 4(a) is to screen all individuals who go through the Indian health care system for potential diabetes problems in order to reduce incidence and to forestall future complications to the maximum extent possible. Section 4(a)(2) accomplishes this purpose in part by requiring effective treatment of high-risk individuals and those who are newly diagnosed, but fails to provide for diabetes screening of every patient who enters an IHS clinic. We recommend that Section 4(a) be clarified to provide for a uniform diabetes screening process to be implemented at all IHS facilities.

Another critical area addressed by S. 1988 is the need to ensure that all IHS health care personnel are fully trained in appropriate techniques for diagnosing and treating patients with NIDDM. The vast majority of cases of diabetes among Native Americans involve the non-insulin dependent version. NIDDM is often characterized by gradual onset, without the acute and immediate symptoms or complications such as [redacted] or

ketoacidosis, which are more commonly associated with the insulin-dependent variety (IDDM). For this reason, NIDDM is generally more difficult to diagnose, and may in some cases go undetected for significant lengths of time. Delays in diagnosis and treatment of NIDDM diabetes can result in the [redacted] incidence of long term complications which in many instances can be reduced or prevented through early diagnosis and control. [redacted].

For all of these reasons, it is essential that all Federal, tribal and other Indian health care providers receive training concerning current methods of prevention, diagnosis, and treatment of NIDDM. Accordingly, we strongly endorse section 4(a)(3) of Senate Bill 1988. We would hope to work cooperatively in a public and private sector effort to develop and provide such programs. In fact, the ADA delivered a specialized training program for health care providers and also supplied 1000 sets of materials as well as trained personnel, at no cost, to the Model Diabetes Care Program last year.

Sections 4(a)(5) and 4(b)(2) of the proposed legislation are also of critical importance to the effort to control diabetes as it affects the Native American population. These provisions direct the Secretary to implement a program designed to disseminate health education information concerning diabetes and to encourage and fund liaison activities among the Federal Government, tribal health care facilities and tribal

communities. The need for increased communication and informational exchange among the federal agencies and tribal health officials in the diabetes field was highlighted by the results of a recent survey of Indian tribes which was circulated by the National Diabetes Advisory Board and several American Indian and diabetes related organizations. The 153 tribes responding to the survey unanimously confirmed the diabetes problem among American Indians, and 97% of these respondents expressed interest in having more information about community education strategies geared to Indian tribes and Indian families.

We wholeheartedly endorse the legislation's directive that the Secretary continue to maintain existing model diabetes clinics, and that the number of model clinic sites be expanded. As detailed in the Annual Reports of the National Diabetes Advisory Board, since 1979 the model clinics have achieved considerable progress in delivering diabetes information and care within a limited number of different Indian tribes. In light of the success of these clinics and the proven needs of the Native American community generally we recommend that at least one diabetes clinic be established and maintained in each of the twelve IHS service units. Although the Bill does provide for model clinics in the vast majority of ~~these~~ administrative units, it does not require any particular geographic distribution of these facilities.

In conjunction with the increased number of model clinic sites provided for by S. 1988, it is important that the resources and information made available through the clinics be disseminated by means of an effective outreach program. In order to achieve this objective, the IHS must be provided sufficient funds to hire qualified personnel within each IHS service area who would coordinate diabetes control projects throughout that area on a full-time basis. Section 4(c)(3) and 4(d) recognize these needs by requiring IHS to maintain appropriate personnel and to develop and implement outreach programs. We recommend that, consistent with these provisions, a full-time "diabetes control officer" be assigned to each IHS administrative area to facilitate outreach from the model clinic facilities.

Conclusion

The relatively modest monetary investments required to implement the provisions of S. 1988 are outweighed by the long-term potential savings that can be achieved through effective prevention and treatment of diabetes within the Native American population. Investment in effective preventive care can dramatically reduce the expenses incurred by the IHS in treating long-term complications such as blindness, amputations and renal failure. For example, approximately 75% of all amputations within the IHS health care system are caused

by diabetes. The cost of these amputations exceeds $3 million annually, exclusive of the cost of rehabilitation. According to research from England and this country, the rate of amputations could be reduced by 40% it proper foot care and therapeutic shoes were made available to diabetic people with circulatory or neuropathic problems. Similarly, interim investments in outpatient education can result in long-term savings resulting from reductions in hospitalization costs. For example, a project funded in Maine by the Centers for Disease Control documented a 39.8% reduction in the number of diabetic individuals hospitalized for all conditions and a 32.2% reduction in the number of hospital days as the direct benefit of outpatient education programs. The significant costs of diabetes-related medical care incurred by the IHS can be greatly reduced through implementation of the preventive educational initiatives that would be required by Senate Bill 1988.

In conclusion, the American Diabetes Association urges the Committee to support these increased efforts to curb the effects of diabetes among Native Americans. We endorse Senate Bill 1988 unequivocally and will gladly assist the Secretary to carry out these important new initiatives.

Thank you for this opportunity to testify.

PREPARED STATEMENT OF THE AMERICAN INDIAN HEALTH CARE ASSOCIATION

Mr. Chairman, the American Indian Health Care Association is pleased to have the opportunity to respond to S. 1988, a bill to establish a program for the prevention and control of diabetes among American Indians. Because diabetes is one of the major causes or contributers to increased morbidity and mortality among American Indians, it is important that such a program become reality. This diabetes prevention and control program would provide the necessary focus for diabetes research, program development, and personnel training so that diabetes can be better prevented and controlled in the American Indian population. The American Indian Health Care Association strongly supports S. 1988.

According to the 1980 census, over 50% of the American Indian population now resides in urban communities across the nation. A large percentage of that population was moved to urban areas as a result of the massive relocation program undertaken by the Federal Government during the 1950's. This urban Indian population continues to maintain strong ties with their respective reservations and the majority continue to be tribal members.

The American Indian Health Care Association has been involved in urban Indian health care for more than ten years. It, and others involved in urban Indian health care, has realized the problems of diabetes for the urban Indian population. The Association has undertaken research, provided workshop sessions, provided speakers for annual conferences, and prepared written materials all pertaining to diabetes in the urban Indian population. In the Progress Report on Urban Indian Health recently prepared by the Association, it was found that frequency of diagnoses for diabetes within the urban Indian health programs (clinics) is comparable to that of the Indian Health Service clinics and hospitals. Therefore, morbidity attributed to diabetes, is a problem for urban Indians and reservation Indians alike.

The American Indian Health Care Association has been engaged in a multi-year study of diabetes in the urban Indian population. The study has sought to determine the major health complications or problems attributed to diabetes and to determine what forms of treatment and control programs seem to have the greatest impact on reducing or controlling diabetes and its complications. This urban Indian diabetes study is comparable to the study undertaken by the Indian Health Services Model Diabetes Control Program because of similar methodology and questions asked. The study has shown that hypertension and cardiovascular diseases are the major diabetic complications found in this population. The study suggests that there are problems associated with weight control, blood glucose testing, medicine taking and exercising that prevent diabetes from being adequately controlled in the urban Indian population. This study indicates a greater need for individualized health education and clinic care so that diabetes can be better controlled or prevented, and its diabetic complications treated or minimized.

The American Indian Health Care Association is hopeful that it, and urban Indian health programs, be allowed to take part in this Diabetes Prevention and Control Program. Urban Indian health programs currently serve more than 187,000 Indians (FY86); it is projected that this urban Indian service population will increase in the coming years. The number of unserved Indians living in urban areas is also a concern that should be addressed.

Mr. Chairman, American Indian and Alaska Native people have always been a mobile population. Indians residing in urban areas maintain strong ties with their tribes and mirror the same low health status of their reservation cousins. To ignore the urban Indian population is to abandon the national goal established in the Indian Health Care Improvement Act, "...of providing the highest possible health status to Indians....". Diabetes knows no boundary. It is important that mechanisms be developed to ensure that care be rendered to Indian diabetics, regardless of whether they live in reservation or urban areas.

Mr. Chairman, urban Indian health programs have sought to provide the highest quality of health services to urban Indians. Because of your gracious support, urban Indian health programs have been able to provide the services so greatly needed and desired by the urban Indian population. Once S. 1988, a bill to establish a program for the prevention and control of diabetes among Native Americans, is implemented diabetes will have a much greater chance of being controlled and diabetic complications minimized or treated in this population. We again thank you for your continuuing support of urban Indian health and for your support of all American Indians.

Thank You.

PREPARED STATEMENT OF THE WARM SPRINGS INDIAN RESERVATION OF OREGON

The Warm Springs Indian Reservation of Oregon is pleased to have this opportunity to present our concerns about diabetes directly to the Senate Select Committee.

For reasons that remain unclear, diabetes has become a serious health problem among members of the Warm Springs Reservation over the past two decades. The prevalence of this disease is increasing at an alarming rate and is between three and four times the national average. The complications of diabetes among many of our known diabetic population have included kidney failure, hypertension, visual disturbances and quite a number of extremity amputations. We fear that unless efforts to prevent and control this disease are increased in our community, the situation will continue to affect larger and larger numbers of our population. The cost of providing treatment for those afflicted with diabetes and its complications has come to represent a significant portion of our total health care expenditures and will continue to increase unless action is taken.

The Confederated Tribes of Warm Springs Reservation of Oregon supports the passage of S. 1988, The Native American Diabetes Prevention and Control Act of 1985.

In addition, the Warm Springs community would like to go on record as requesting that consideration be given to selecting Warm Springs as a demonstration site for a model project for Diabetes Prevention Control.

Oglala Sioux Tribe
Phone (605) 867-5821
Box 468
Pine Ridge, South Dakota 57770

Office of the President
OGLALA SIOUX TRIBE

April 22, 1986

Honorable Senator John Melcher
United States Senate
Select Committee on Indian Affairs
Washington, D.C. 20510

Dear Senator:

The Pine Ridge Reservation of the Oglala Sioux Nation and the staff of the Pine Ridge Indian Health Service applaud and support the initiatives outlined in S. 1988. Representatives from the Pine Ridge Indian Reservation attended the Senate hearing on the proposed Bill in Washington in April.

The effects of diabetes mellitus upon the Native American population is close to the hearts of our people. Diabetes is becoming an epidemic among Native Americans. At Pine Ridge, diabetes is present in 36% of our elders, contributing to a diabetic death rate of 25.4%. A devastatingly high percentage rate compared to 3% and 9.6% respectively for non-Indian Americans.

Diabetes is not just an Indian concern, it's a national tragedy. As diabetes increases it comes closer to robbing American of its last surviving link with its origins. The Pine Ridge Oglala Sioux have succeeded in maintaining its cultural heritage when other tribes have failed. Pine Ridge and other Aberdeen Area reservations are among the few regions of the nation where the Indian language, arts, culture and religion have survived. At Pine Ridge, one can still find medicine men, healing ceremonies, sweat lodges and the Sun Dance ceremony.

The existence and survival of the uniquely American culture is testimonial to the Native Americans' determination to survive as a race and culture. Its very existence allows Americansto witness a living part of its heritage. Today, our children may visit a reservation and see firsthand a part of its history, instead of seeking it out in books and museums of past civilizations. Let us hope that our children and grandchildren will have the same opportunity.

The Pine Ridge Indian Health Service in cooperation with the people of Pine Ridge Reservation seek to identify methods to treat diabetes, educate the diabetic Indian and prevent the development of diabetes in Native Americans. However, such endeavors cannot be accomplished relying solely on research based on non-Indian population or using educational material which is culturally alien to the Indian. We must also investigate genetic and metabolic differences between Indian and non-Indian diabetics. In order to do this, we must conduct research upon Indians of high blood quantum living in Indian communities.

S. 1988 proposes additional diabetes model sites in locations other than the Aberdeen Area. This is needed but one must also consider the availability of full blooded Indians in the respective populations. Pine Ridge offers such a population relevant to the research needs of the S. 1988 Bill proposal.

We acknowledge the existence of two diabetes model projects in the Aberdeen Area. Such projects are helpful to the Pine Ridge population but when one considers Winnebago has a diabetic population of 49 and Fort Totten 61, one must consider Pine Ridge with a diabetic population of 661 to be an ideal site for a model project.

The Senate Select Committee on Interior and Insular Affairs and the United States Public Health Service may count on Pine Ridge Service Unit and the Aberdeen Area Office to give full support and research into diabetes.

Please let us know your support by establishing a model diabetes clinic at the Pine Ridge Service Unit, Pine Ridge Indian Reservation.

Sincerely,

Joe American Horse

JOE AMERICAN HORSE
President
Oglala Sioux Tribe

RESOLUTION NO. 86-18XB

RESOLUTION OF THE EXECUTIVE COMMITTEE
OF THE OGLALA SIOUX TRIBE
(An Unincorporated Tribe)

RESOLUTION REQUESTING TO INSERT LINE 13(F) ABERDEEN AREA OF S.1988 TO ESTABLISH A PROGRAM FOR THE PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS.

WHEREAS, in reference to S.1988, on Page 7, line 8 through 12, states that within two years after the date of the Act, the Secretary shall establish and maintain a Model Diabetes Clinic in each of the following locations:

Line 8 (A) the Navajo Reservation
Line 9 (B) the Papago Reservation
Line 10 (C) Montana
Line 11 (D) Minnesota
Line 12 (E) Hawaii, and

WHEREAS, the Aberdeen Area predominantly is serving the Sioux Nation populations. We wish to establish a Model Diabetes Clinic for the Aberdeen Area. Currently the Aberdeen Area is not included in S.1988, now

THEREFORE BE IT RESOLVED, that the Oglala Sioux Tribal Health Authority, Inc. (Health Board) is hereby requesting that the inclusion of the Aberdeen Area be made following Hawaii, as Line 13 (F) Aberdeen Area. We wish to establish a Model Diabetes Clinic in the Aberdeen Area.

C-E-R-T-I-F-I-C-A-T-I-O-N

I, as undersigned, Secretary of the Executive Committee of the Oglala Sioux Tribe, hereby certify that this resolution was adopted by the vote of: 4 for; 0 against; and 1 not voting, during a REGULAR Session held on the 24th day of APRIL, 1986.

Nancy S. Hussman
NANCY S. HUSSMAN
Secretary
Oglala Sioux Tribe

A-T-T-E-S-T:

Joe American Horse
JOE AMERICAN HORSE
President
Oglala Sioux Tribe

Received
APR 24 1986
Pine Ridge
Agency

NATIONAL CONGRESS OF AMERICAN INDIANS

1986 APR 25 PM 10:35

April 21, 1986

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Cheyenne & Creek Nations

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Rincon Band of Luiseno

SOUTHEASTERN AREA
Billy Cypress
Miccosukee Tribe

Honorable Mark Andrews
Chairman
Senate Select Committee on Indian Affairs
838 Hart Building
Washington, D.C. 20510

Dear Chairman Andrews:

We would like to submit as part of the hearing record on S. 1988, Native American Diabetes Prevention and Control Act of 1985, the results of a diabetes survey sponsored by the National Congress of American Indians and the National Indian Health Board in conjunction with the National Diabetes Advisory Board.

The survey was sent to all tribes, and the responses show an overwhelming desire for more educational materials and activities aimed at prevention of diabetes. We would hope that the entire survey analysis could be made part of the record, but if it is too lengthy, then we would suggest that the first two pages which summarize the responses would be included.

The National Congress of American Indians supports S. 1988, but we are concerned about the inclusion of Native Hawaiians as IHS recipients. The diabetes and other health problems of Native Hawaiians are severe and must be addressed. We would suggest that the Native Hawaiian portion of S. 1988 be incorporated into S. 2243, legislation to improve the health status of Native Hawaiians.

We support the bill's mandate to IHS to make diabetes prevention a more integral part of their health care delivery system, the expansion of model diabetes clinics and the increased training regarding diabetes for IHS personnel. The Indian Health Service, to their credit, has placed increased emphasis on diabetes in the past several years by starting diabetes clinics, offering diabetes workshops and producing eductional materials. The problem with their effort, and a potential problem with S. 1988, is lack of money

to reach all the Native people who are at risk to have diabetes or who already have diabetes and need assistance.

Thank you and the members of your Committee for your active interest in the problem of diabetes among Native Americans. We are pleased to give our support to your efforts.

Sincerely,

Suzan Shown Harjo
Executive Director

Analysis of Responses to Indian Diabetes Questionnaire

1. Are you aware of the diabetes problem among American Indians?

   100% yes 0% no

2. What percent of adults in your tribe have diabetes?

   17% (This was the average percent provided by respondents who used only percents in their answer.)

   4.5% (This was the average percent provided by respondents who used only numbers in their answer.)

   9% (This was the average percent provided by all respondents.)

3. Please check the diabetes complications that affect members of your tribe. (The purpose of this question was to ascertain information about the general awareness of diabetes complications among tribal health workers.)

   70% responded that kidney failure affected members of their tribe.

   68% responded that blindness affected members of their tribe.

   80% responded that leg/foot amputations affected members of their tribe.

   52% responded that pregnancy complications affected members of their tribe.

4. Is the tribe helping to pay for some of the costs of diabetes care?

   35% yes 65% no

5. How much has your tribe spent for diabetes care during the past fiscal year?

Screening	$5,425
Renal dialysis	$39,914
Other diabetes associated costs	$23,649

   (These figures represent average amounts spent per tribe per category of diabetes activity. The figures do not include money spent by IHS for diabetes services.)

6. What activities are being conducted by the tribe to reduce diabetes problems?

   --The individual answers to this question are listed separately at the end of this summary (page 3). There was a wide range of responses but several indicated that no diabetes activities were being performed. Of those that were conducting activities, many of them had to do with screening. Several tribes indicated that they had regular diabetes clinics and there were a few who provided diabetes education and counseling services, particularly in the areas of diet, exercise, stress management, and support groups.

7. Has your tribe developed any materials to educate your community about diabetes?

   22% yes 78% no

8. Would technical assistance or a guidebook be helpful?

   91% yes 9% no

9. Since 91% of the respondents indicated that technical assistance or a community guidebook to be used by tribal health workers would be useful, the following depicts the areas about which they are interested in obtaining more information.

   80% are interested in screening efforts for early detection of diabetes.

   93% are interested in education directed at families regarding how to prevent or delay the onset of complications.

   72% are interested in how Indian Health Service and the tribe can work together to conduct public awareness activities about diabetes.

   97% are interested in community education strategies and health promotion activities such as exercise, weight control, and general nutrition geared to Indian tribes.

   76% are interested in more information about educational resources available to communities (programs, materials and technology).

10. Are you aware of the Indian Health Service Model Diabetes Program?

    54% yes 46% no

11. Have you or members of your tribe received assistance or training from the Model Diabetes Program staff?

    33% yes 67% no

12. In what other areas (besides those listed in question 9) would you like assistance?

    --The individual answers to this question are listed separately at the end of this summary (page 13). As with number 6, there were a variety of responses to this question. However, several respondents mentioned items already listed in number 9. Others indicated a need for more culturally appropriate educational materials for Native Americans that are written for people with limited reading skills. Several respondents also indicated a need for "How to" information describing methods for heightening public/community awareness about diabetes. A few also asked for information regarding motivation strategies.

13. Would your tribe help us by reviewing any materials that might be developed from this effort?

    99% yes 1% no

PHONE (605) 867-5678 - 5504

Oglala Sioux Tribal Health Services
P. O. BOX 468
PINE RIDGE, SOUTH DAKOTA 57770

April 21, 1986

Mr. John Melcher
Ranking Minority Member
United States Senate
Select Committee on Indian Affairs
Washington, D.C. 20510

Dear Mr. Melcher:

In reference of S.1988, on Page 7, line 8 through 12, states that within two years after the date of the Act, the Secretary shall establish and maintain a Model Diabetes Clinic in each of the following locations:

Line 8(A) The Navajo Reservation
Line 9(B) The Papago Reservation
Line 10(C) Montana
Line 11(D) Minnesota; and
Line 12(E) Hawaii.

We, hereby, request that the inclusion of the Aberdeen Area be made following Hawaii as Line 13(F) Aberdeen Area.

Justification: The Aberdeen Area is predominantly is serving the Sioux Nation populations. We wish to establish a Model Diabetes Clinic for the Aberdeen Area.

Sincerely,

Esther DeSersa

Esther DeSersa, Director
OST Health Services

CONCUR:

Arta Carlow

Arta Carlow, President
Tribal Health Authority, Inc.

cbh

RESOLUTION NO. 86-01HB

RESOLUTION OF THE OGLALA SIOUX TRIBAL HEALTH AUTHORITY, INC.
OF THE OGLALA SIOUX TRIBE
(An Unincorporated Tribe)

RESOLUTION REQUESTING TO INSERT LINE 13(F) ABERDEEN AREA OF S.1988 TO ESTABLISH A PROGRAM FOR THE PREVENTION AND CONTROL OF DIABETES AMONG NATIVE AMERICANS

WHEREAS, in reference to S.1988, on Page 7, line 8 through 12, states that within two years after the date of the Act, the Secretary shall establish and maintain a Model Diabetes Clinic in each of the following locations:

Line 8 (A) the Navajo Reservation
Line 9 (B) the Papago Reservation
Line 10 (C) Montana
Line 11 (D) Minnesota; and
Line 12 (E) Hawaii, and

WHEREAS, the Aberdeen Area predominantly is serving the Sioux Nation populations. We wish to establish a Model Diabetes Clinic for the Aberdeen Area. Currently the Aberdeen Area is not included in S.1988, now

THEREFORE BE IT RESOLVED, that the Oglala Sioux Tribal Health Authority, Inc. (Health Board) is hereby requesting that the inclusion of the Aberdeen Area be made following Hawaii, as Line 13 (F) Aberdeen Area. We wish to establish a Model Diabetes Clinic in the Aberdeen Area.

C E R T I F I C A T I O N

I, as undersigned, Secretary of the Oglala Sioux Tribal Health Authority, Inc. (Health Board) do hereby certify that this resolution was adopted by a vote of 4 for; 0 against and 0 not voting during a SPECIAL SESSION held on the 21st day of April, 1986.

Esther DeSersa
Secretary, OST Health Authority, Inc.
acting

ATTEST:

Arta Carlow
Arta Carlow, President
OST Health Authority, Inc.

62-673 (164)